CONSTRUCTING THE INTELLECTUALLY DISABLED PERSON AS A SUBJECT OF EDUCATION: A DISCOURSE ANALYSIS USING Q-METHODOLOGY

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ABSTRACT

The education of intellectually disabled (ID) people is constructed within mass education systems as a problem requiring specialised intervention, separation from “normal” school contexts and the application of professional expertise. A social model of disability resists these practices from a human rights perspective and underpins an inclusive education approach. In this study, a post-structuralist disability studies theoretical framework, drawing particularly on the work of Foucault, was used to examine discourses that construct the intellectually disabled person as a subject of education. The study was conducted in Buffalo City, South Africa at a time when an inclusive education policy is being implemented in the country. The research questions were: What discourses are deployed in the representation and educational practices of those identified as ID? What are the effects of these discourses in constructing the ID subject and associated educational practice?

The study utilises Q-methodology, a factor analytic method that yields whole patterns of responses for analysis. A process of sorting selected statements along the dimension of agree to disagree was completed by three groups of participants, namely adults with ID, parents of people with ID and professionals working with ID. Discourses of representation and of educational practice were identified through statistical and interpretive analysis, following the discourse analysis school of Q-methodology.

The findings of this study reveal the operation of power in a medico-psychological gaze that makes ID visible and supervises disability expertise within education. Representations of ID suffused with religious notions support the exercise of pastoral power by disability experts. Human rights discourses in education can marginalise ID people if applied uncritically. Fixed notions of impairment constrain an intellectually disabled subject who is vulnerable and incompetent. This study argues instead for a theory of (poss)ability, underpinned by an understanding of the situational and shared nature of competence and a fluid conception of impairment. Human rights should be supplemented by an ethics of care and belonging in the community (*ubuntu*). A research agenda supporting this effort would examine the ways in which ID people work on themselves as subjects (subjectivisation) and explore the potential for resistance in this process.

ACRONYMS

CYWID	Children and Youth with Intellectual Disability
DA	Discourse Analysis
DBST	District Based Support Team
DICAG	Disabled Childrens' Action Group
DSAA	Down Syndrome Association Amathole
DSSA	Down Syndrome South Africa
ECD	Early Childhood Development
EWP 6	Education White Paper 6
FSS	Full Service School
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
ICD-10	International Statistical Classification of Diseases and Related Health Problems Disabilities Tenth Revision
ID	Intellectual Disability
IQ	Intelligence Quotient
NCESS	National Committee on Education Support Services
NCSNET	National Commission on Special Needs in Education and Training
NEPI	National Education Policy Initiative
RS	Resource School
SALC	South African Law Commission
SRV	Social Role Valorisation
SS	Special School
SSS	Scientific Study of Subjectivity
UN	United Nations
UPIAS	Union of the Physically Impaired against Segregation
USA	United States of America
WHO	World Health Organisation

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My interests and understanding of intellectual disability and inclusive education has grown over many years through engagement with colleagues and friends from REHAB, the Sisonke consortium and the Department of Education at the University of Fort Hare. I am grateful to them for their collaboration. I would like to thank the Down Syndrome Association Amathole for their ongoing support to parents and the assistance that they offered in this study, especially Denise Taylor and Linda Davis. I am very grateful to the district officials and school principals for arranging interviews. I thank the participants in this study and I appreciate not only their time but also their willingness to share their carefully thought out and strongly felt views.

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APPENDIXES

For the purposes of examination, the appendixes are presented in a separate book. This is for ease of reference as the reader will need to refer to the tables in the appendixes to understand the results sections in chapters 6 and 7 as well as to refer to factors summaries in chapter 8.

CHAPTER 1: INTRODUCTION

> 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 child centred 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. (Salamanca Satement, 1994, pp. viii-ix)

The Salamanca Statement quoted above is an endorsement and a public acceptance of inclusive education. It was declared in the international arena as the most effective response to the educational needs of children who had previously received segregated or no education on the basis of disability or other forms of difference. This international trend was adopted (with disclaimers) by the South African Department of Education in the *Education White Paper 6: Special needs education: Building an inclusive education and training system* (Department of Education, 2001). The White Paper presents the response to learners within the education system who are classified as experiencing barriers to learning, including those caused by disability.

As a parent and professional, I have been part of the exciting process of developing inclusive education in South Africa. I have given input to policy development, implemented inclusive education projects, seen my son through inclusive and special schooling, and trained teachers in inclusive education. In so doing I was struck by the different understandings of disability amongst people involved in the project of education for disabled people. Positions that were taken regarding inclusive education, special schooling and the nature of disability seemed resistant to change. Discussions generally shed more heat than light when opposing views were adopted in the numerous education forums set up to support these changes.

Reasoned argument was futile as advocates of inclusive education lined up against the special school lobby. No sooner was some ground gained, on either side, than it became apparent that completely different meanings were attached to concepts about which we thought we had agreed. In my particular focus on intellectual disability, I realised that educational practices could not be agreed upon insofar as we had different conceptions about what it means to be intellectually disabled. I therefore embarked on the current project to understand better how the way in which disability is understood interacts with views on educational practice. In this introductory chapter, I shall give an overview of the project and outline the main points that have emerged from the research.

Intellectual disability within educational practice forms the key focus of this research. From the start I wish to acknowledge that terminology is politically loaded. Given this, I shall, for the purpose of this study, use the term intellectual disability, as the British term "learning disability/difficulty" has different connotations in the South African context. The term "mental retardation", which is in common use in the United States, is considered to be pejorative in the South African context. There is an ongoing debate about the use of "people first" terminology, that is "people with intellectual disability" as opposed to the term "intellectually disabled people". While the former is preferred by people who are categorised as intellectually disabled (Central England People First Limited, 1996-2000), the latter has the advantage of foregrounding social practices, which disable the individual, rather than placing the emphasis on the person him- or herself and reifying the disability as something that a person "has". I have decided to use both terms interchangeably, thereby acknowledging both sides of the debate. I make a crucial terminological distinction between intellectual impairment and intellectual disability in a discussion of the social model of disability in chapter 2. I also note the use of derogatory labels such as "idiot" and "imbecile" in chapter 3 within the historical context in which they occur.

Research questions

The focus of this research is educational practice, as it moulds and shapes understandings of intellectual disability as a problem for education. It explores the ways in which discourses of representation of intellectually disabled people and associated educational practices make possible certain ways of doing and being and restrict other possibilities. The project undertaken in this study is framed by three research questions:

1. What discourses are deployed in the representation of those identified as intellectually disabled in Buffalo City, South Africa?

This question seeks to explore the ways in which intellectual disability is figured in the study context. It arises from a theoretical perspective that rejects assumptions about the essential nature of intellectual disability and seeks to examine the way in which the object of intellectual disability comes to be understood within discourse (see chapter 2). In addition, this question approaches all discourses of intellectual disability as epistemologically equivalent, removing the privilege of a bio-medical discourse and seeking to delineate submerged discourses.

2. What discourses are deployed concerning the practices of education of those identified as intellectually disabled in Buffalo City, South Africa?

Arising from the same theoretical commitment as for question 1, this question is not concerned with a comprehensive account of forms of educational practice and adjudicating upon their relative effectiveness. Rather it aims to identify discourses that describe and prescribe educational conduct and to consider the power effects of such discourses.

3. What are the effects of these discourses in constructing the intellectually disabled subject and associated educational practice?

The third question is based on the understanding that representation and practice are not distinct from each other. The way in which an object is understood is both a *product* and *productive* of the practices associated with it. As such the separation between questions 1 and 2 is an artificial one, intended as an analytic tool. This third question collapses the representation/practice divide and examines the effects of discourses identified in the first two questions.

The focus of these questions arises from a specific theoretical framework adopted in this study, that of critical pos-structuralist disability studies. I shall provide a brief introduction to this framework below.

Critical post-structuralist disability studies

The current study is located within the discipline of Disability Studies, a relatively new academic field that is closely tied to a political project of disability rights (Meekosha, 2004). Fundamental to the project is a rejection of essentialist views of disability as a biological determinant of social status and the adoption of what is termed a social model of disability

(Oliver, 1990). This model breaks the link between the biological (the impairment or organic defect of the body) and the social (the disability or social barriers maintained by society). Since impairment is viewed as individual and idiosyncratic, it is the experience of disability, arising from society's inability to adapt for people with impairments, that forms the basis of political activism (Oliver, 1996). Disability Studies (in its broadest sense) is aligned with the emancipatory intent of the disability rights movement, based on a rejection of biological determinism and the centrality of the participation and voice of disabled people in disability research. However, the binary of impairment and disability that is adopted in the social model is critiqued within a critical post-structuralist approach.

While this binary opens up disability for social action, impairment is figured as an individual property that has a fixed, biological nature, subject to medical authority (Hughes & Paterson, 1997). This forced dichotomy, between the individual impairment and the socially constructed disability, led disability scholars to ignore impairment as unimportant or to view it as of little theoretical or political interest. Concerns relating to impairment, such as the lived experience of impairment, the different effects of impairment types and the uneasy relationship with the medical profession, were minimised in the interests of a politically expedient solidarity based on a shared experience of disablement by society (Shakespeare, 2006).

At its core the binary of disability/impairment poses questions about the relationship between the individual and society. Is the individual impairment prior to and causal of the condition of disability? If so, then the focus of action is to minimise the impairment, largely though bio-medical and therapeutic intervention, so as to maximise social participation. If, on the other hand, it is society that creates the disability through disabling practices, then participation in society should be achieved through social pressure. Either of these approaches taken to their logical extremes creates an absurd situation of either biological determinism in a medical focus or the disappearance of impairment in a political project.

In order to avoid these extremes, I theorise the disability/impairment debate within the theoretical framework of a post-structuralist understanding that draws on Foucauldian theory of the individual as a subject constructed within discourse. In this way the relationship between the individual and society is reformulated as mutually constructive. This perspective requires a decentreing of the rational self as an autonomous agent, free to act upon the world. Rather the subject is viewed as a product of power and knowledge.

Within a post-structuralist, Foucauldian frame, the notion of knowledge as the progressive revelation of a truth that is already present, but hidden within the object under investigation, is rejected. Knowledge is not viewed as orderly, continuous, progressive and sequential but rather as productive of the subject and inextricably linked with power (Popkewitz & Brennan, 1998). In this frame, the notion of an integrated, unitary self is destabilised and the self is seen rather as a particular construction of subjectivity made possible within certain conditions (Henriques, Hollway, Urwin, Venn, & Walkerdine, 1998). These conditions are manifest in discourse that “speaks” the subject into being. Thus, for example, a eugenic discourse enables certain ways of constructing the intellectually disabled subject (as possibly threatening, with a dangerous sexuality) and forbids others (for example, as a citizen with rights). In this post-structuralist view the focus moves toward understanding the intellectually disabled subject as a contingent social construction, changing over time and space, formed by (and which in-forms) educational practice, making up people in certain ways that constrains their field of action. Knowledge, therefore, cannot be dissociated from power.

In developing an understanding of how power operates to make up the intellectually disabled subject I draw heavily on the work of Michel Foucault (see chapter 2). Utilising his insights, I discuss how the intellectually disabled subject is made visible through the disciplines of Medicine, Psychology and Special Education. Procedures of definition, diagnosis and prescriptions of the correct course of action to be taken figure the intellectually disabled person in certain ways. For example, intelligence testing defines a norm against which the individual is ranked. The intellectually disabled person is deemed to be lacking in the essential quality of intelligence and therapeutic procedures are invoked. However, there is nothing inherent in a condition of intellectual disability that requires that it be described in this way. The test scores are not part of a material object of intellectual disability but rather they serve to construct a particular category of person on whom it is incumbent to respond in certain ways. In this way a certain *kind* of person is constructed (Hacking, 1999), in our discussion, the intellectually disabled person.

Viewed in this light, the practice of education for intellectually disabled people cannot be seen as the neutral application of scientific evidence to a known entity. Rather it is a practice that constructs the object that it seeks to govern. The practice of special schooling, for example, constructs two categories of children — those that belong in a regular school and those that require different forms of placement. This division is authorised and given a moral justification by claims to knowledge of the truth about intellectual disability by the medico-psychological authorities, who are responsible for the diagnosis and management of the condition (Rose, 2007). In educational practice for intellectually disabled people, this expertise is constituted into the discipline of Special Education.

Given the strong claims to truth exercised by the medico-psychological gaze, the operation of power becomes obscured. Certain forms of practice become taken-for-granted as being in the best interests of the individual with an ethical and moral rationale. The expert is required to know the individual in detail — their thoughts, habits and what they may become — and the individual comes to know him- or herself in this way, thereby owning to the identity offered by this detailed knowledge in the practice of pastoral power (Foucault, 1982), which will be further discussed in chapter 2.

Discourse and language are central to the method of study of the mechanism whereby the object of intellectual disability and subjects of educational practice are formed. Discourse, in this understanding, does not serve to describe a pre-existing reality ‘out there’ but rather it constructs a field of action in which certain ways of acting, being and understanding are made possible and others are restricted (Macleod, 2002). Thus, to understand intellectual disability discourse is taken as the object of study. The methodology used in this study allows for distinguishing the domain of discourse of intellectual disability and within this, to identify specific, distinct discourses that are deployed to different effect in social intercourse.

Noting that the notion of discourse is contested, I shall make explicit the understanding adopted in this study. Discourse is not only about language that describes a particular object. Rather it encompasses language, social practices and material arrangements. This is not to deny materiality or to suggest that there is no reality outside of discourse but rather to recognise that the material world can only be understood through discourse. Discourse imposes a grid of understanding of reality. It allows for certain possibilities and makes others unthinkable because they fall outside of available discourse. In this way discourse is more than what is said about something that exists in the real world — rather it makes up the object that is under discussion.

The project of understanding the object of intellectual disability requires a recognition that it is not an unproblematic thing in the world that has always remained constant over time (Rapley, 2004). One way of destabilising this claim is to view it through an historical and cultural lens by means of a review of the literature (see chapter 3). What comes into view is an object that is increasingly regulated, differentiated and brought under disciplinary control. Educational practice both governs and sustains representations of intellectual disability in ways that are often not immediately apparent from the rhetoric. This does not occur in a vacuum but in a certain historical and political context, which in this study is the relatively young post-apartheid democracy of South Africa in the district of Buffalo City.

Context of the study

This study takes place in the context of a recent history of apartheid and human rights abuses on the grounds of race. Issues of social justice are central to South African democracy and extend to its entire people. The purpose of the South African Constitution, as stated in the Preamble, is to:

- Heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights;
- Lay the foundations for a democratic and open society in which government is based on the will of the people and every citizen is equally protected by law;
- Improve the quality of life of all citizens and free the potential of each person; and
- Build a united and democratic South Africa able to take its rightful place as a sovereign state in the family of nations. (Republic of South Africa, 1996, p. 1243)

Educational policy deriving from the Constitution requires compulsory (though not free) education for all children. The initial challenge that this posed was the integration of a fragmented system that provided separate education for different race groups, with Africans being the least well provided for, into a single education system. The goal of educational policy was to develop a just and equitable system that would provide good quality education for all (Mothatha, 2000). The history of exclusion of disabled children from education necessitated a specific policy development process, focusing on special educational needs and school support services (Department of Education, 1997). This culminated in the publication of *Education White Paper 6. Special needs education: Building an inclusive* *education and training system* (Department of Education, 2001). This document adopts an inclusive education policy that will proceed incrementally and will continue to make use of special schools and professional expertise, distributing this more widely than occurred under apartheid (see chapter 4). The 20 year implementation timetable adopted in the White Paper is massively behind schedule but a national strategy for screening, identification, assessment and support has been developed and is being incrementally implemented. Pilot projects have been completed in 30 districts country wide and these districts continue to be developed to improve their capacity for delivering inclusive education.

A parallel and supportive process has been that of the disability rights movement within South Africa that was able to make significant gains for disabled people in the new democracy. The strategy of the leading organisation of the disability rights movement of South Africa, Disabled People South Africa (DPSA), was to align the struggle of disabled people with that of liberation for racial discrimination (Howell, Chalklen, & Alberts, 2006). As a result the movement was successful in ensuring that disability issues are included in a whole range of policies. The human rights aspect of disability has also been bolstered by the recent adoption at the United Nations of the Convention on the Rights of Persons with disabilities and its ratification by South Africa (United Nations, 2006). Thus the context for disabled people in South Africa is one of a strong human rights support base and a great deal of enabling policy and legislation.

Despite these gains, South Africa is experiencing numerous problems with the implementation of ambitious policy. This is reflected in current concerns of government with enhancing service delivery in an attempt to close the gap between policy and implementation. Poverty and unemployment remain a reality for a large section of the South African population, most of whom are black (Southall, 2007). In many areas of the Eastern Cape families are dependent on remittances from the urban areas and the monthly social grants that the State provide for pensioners and disabled people (Nattrass, 2007). The provision of quality education for all South African children remains an elusive goal, despite massive expenditure to this end (Kanjee, 2007). Issues of poverty and poor quality education in regular schooling provide the background within which the education of intellectually disabled people must be located. In this context, inclusive education continues to be contested as a means for educating children with intellectual disability (Engelbrecht, 2006). The specific context of Buffalo City will be discussed in chapter 5.

Methodology Used in this Study

In this study a discourse analytic methodology was sought that would delineate a range of discourses deployed in the study area of Buffalo City. Such a method, in a post-structuralist frame, should not depend on pre-defining the object of intellectual disability but rather should allow for multiple ways of constructing it as an object of knowledge to emerge through participant engagement. An additional methodological requirement was that it should enable the participation of intellectually disabled people themselves, taking into account the disability studies framework of this study and the imperative to engage disabled people themselves in research (Goodley, 2004; Scior, 2003; Walmsley, 2001, 2004). This study makes use of Q-methodology for this purpose, adapting the method in line with a discourse analytic school of the method (W. Stainton Rogers, 1998).

Q-methodology was originally developed by William Stephenson, a researcher in the psychological laboratories of Spearman and Burt in the United Kingdom in the 1920s and 1930s (S.R. Brown, 1997). These researchers made use of factor analytic techniques (in what Stephenson termed R-methodology) that allowed for the identification of groupings of highly inter-correlated tests or variables (termed factors) that were then theorised as underlying latent psychological variables, such as intelligence. Subsequent individuals could then be tested with respect to this variable and ranked relative to statistical norms (S.R. Brown, 1980).

Stephenson made two innovations to this method in his development of Q-methodology. Firstly, the data gathered differs from R-methodology in that it consists of evaluations, such as “agree with” or “disagree with”, by the participants of items with which he or she is presented. This requires an active decision-making process by the participant as he or she constructs meaning through interaction with the research instrument (Watts, 2002). Secondly, the data is analysed as a whole pattern as opposed to seeking individual differences (Kitzinger, 1999). In keeping with the notion of discourse as constructing a field of possibility it is anticipated that the range of patterns that are constructed by individuals will cluster together in a finite range of diversity. In this study it is argued that these clustered patterns can be viewed as accounts or as discourses.

In this study, two Q-sets were developed, namely a) Q-set A, a set of statements concerning representation of intellectually disabled people and b) Q-set B, a set of statements concerning educational practices for intellectually disabled people. Participants were then asked to sort these statements along the dimension of relative dis/agreement, ensuring that every statement is allocated a slot on the scale (-3 to +3 in Q-set A and -6 to +6 in Q-set B). The data for analysis consisted of a sorting pattern for each individual, termed a Q-sort, and the participants' explanatory comments. Three sets of participants, a) intellectually disabled adults, b) parents of intellectually disabled people and c) professionals working with intellectually disabled people completed Q-sorts for Q-set A. The definition of an intellectually disabled person for the purpose of participant selection was simply a person who has been an ongoing recipient of services addressed toward intellectual disability. Four Q-studies were conducted with the data. Q-set B was completed by parents and professionals only and analysed as a whole, forming Q-study B.

Through the application of the statistical analysis of Q-methodology, factor analytic patterns were derived. Factor solutions for each Q-study were adopted on the basis of a) providing clear factors (with an eigenvalue greater than one) and b) allowing the greatest number of participants to load onto any one of the factors (see chapter 5). Eighteen accounts (termed as such because of their relative variability and instability, see chapter 5) and four discourses of representation of intellectual disability were identified using Q-set A. Six discourses of educational practice resulted from participant interaction with Q-set B. These were then interpreted and related to each other and analysed in the light of the theoretical framework and the literature. This analysis supports the arguments made below.

Contributions of this Study and Central Arguments

An analysis of discourses deployed in the Buffalo City district reveals a distinction between a) a medico-psychological gaze and b) disability expertise. The former is the gaze that makes intellectual disability visible and reveals its the hidden truth about intellectual disability through diagnostic techniques. Armed with this superior form of knowledge, the medico-psychological authority is empowered to prescribe the appropriate educational, psychological or medical intervention. The gaze is exercised by doctors, psychologists and, to some extent, therapists, and fixes impairment by means of diagnostic mastery. Disability expertise, on the other hand, is exercised by teachers with knowledge of special education, who practice under the authority of the medico-psychological gaze. This expertise incorporates an understanding of disabled people in terms of their habits, their needs and their overall nature as well as the necessary love and compassion. I argue that disability expertise is deployed within educational settings in such a manner that renders education of disabled people outside of the expected area of competence of the regular school and teacher. Thus inclusive education intent can be undermined by a dependence on disability expertise that holds impairment as a static property of the individual. The notion that expertise can only be exercised under the sanction of the medico-psychological gaze excludes the regular classroom teacher from legitimate, effective engagement with intellectually disabled learners.

The operation of human rights discourses is noted in this study as serving a range of educational practice from full inclusion to separate care and protection. I argue that a struggle for human rights for intellectually disabled people should not be an uncritical one. The construction of the individual as rational, autonomous and an active agent implied within a discourse of human rights poses certain problems for intellectually disabled people. The notion of competence as situational and shared and the development of an ethics of care are proposed in this study as productive avenues for supporting rights based struggles.

The saturation of many of the representational discourses with Christian ethics is reflected in the exercise of pastoral power in educational practice. Practices of differentiation, exclusion and expertise are deployed in the best interests of the child. These practices depend upon a thorough knowledge of the individual by the professional. The disabled person is then called upon to own this identity. In this way, the disability professional exercises a pastoral power in caring for and knowing their flock of disabled learners. In the current study, this professional form of pastoral power is bolstered by Christian ethics that are adopted by parents, professionals and intellectually disabled people themselves. A potentially positive form of identity is found in parents’ view of their intellectually disabled children as a blessing, as this is one of the few accounts that acknowledges the potential contribution of the intellectually disabled person to the caring relationship.

Ultimately this study has examined practices of power — the power to define intellectual disability and its government. However, as Hook (2007) reminds us Foucault saw power as diffuse and located at multiple points and this allows then for resistance at multiple points.

What then are the possibilities for resistance to the power effects of a fixed reified view of disability?

I propose that there is a need for more research and a better understanding not only of subjectification (whereby individuals are made subjects) but also subjectivisation (the work that individuals do on themselves to make themselves governable). This would entail the engagement of intellectually disabled people themselves in exploring their own subjectivity. However, in the context of poverty, abuse and discrimination against disabled people, such a research agenda should be complemented by work that seeks to improve the material conditions of disabled people.

In terms of educational practice, fluidity, uncertainty and the notion of competence as both situational and distributed between participants are promising avenues to explore within the burgeoning field of disability studies in education (Gabel & Peters, 2004; Goodley, 2007; Ware, 2001). This line of inquiry should be based on an understanding of impairment within discursive context, rather than as a biologically static entity. Finally I argue for a watchful eye to be cast on inclusive education policy in South Africa lest it be found to reduplicate the very practices of exclusion and special education that it was set up to address in the first place.

I conclude my dissertation by arguing for what I term a theory of *(poss)ability* as opposed to (in/dis)ability. Such a theory would abandon a concept of impairment as a fixed static entity and adopt a stance of fluidity, uncertainty, hope and potential. It would construct educational practice as dealing with intellectual disability as an element of diversity that requires certain forms of support. The contexts of support become the focus rather than the static individual impairment of the learner. In an understanding of (poss)ability the potential of the individual is linked to the ways in which competence can be shared and distributed in caring relationships. It requires an ethics of care that supports the development of interdependence and belonging in the community.

Chapter Outlines

Chapter 2 explicates the theoretical framework adopted in this study. A background is provided to an understanding of disability within a social model of disability. The binary of disability/impairment is scrutinised from a post-structuralist feminist understanding of the similarly constructed sex/gender binary. A review of Foucault's understanding of power, with particular reference to the relationship between the individualising power of the disciplines to the description of populations in the deployment of bio-power, underpins a discussion of the practice of the medico-psychological gaze and expertise. Pastoral power is unpacked as an apparatus of governmentality that is particularly relevant to the government of disability. Given the centrality of discourse to a Foucauldian understanding of power and knowledge, the understanding of discourse adopted within this study is clearly set out. In cognisance of critiques of post-structural theorising as unhelpful to emancipatory projects, a discussion of the possibilities for resistance and human rights is presented. This chapter concludes with a consideration of the application of theoretical insights on representation and subjectivity derived from feminist disability studies.

In chapter 3, key moments that have informed current understandings of intellectual disability are identified. These moments are not presented in a chronological progression toward an ever more enlightened understanding of intellectual disability. Instead it is argued that they constitute points where fundamental shifts in understanding took place and that have traces in the present in a taken-for-granted knowledge of intellectual disability. The events that are considered are the confinement of the insane, the development of the philanthropic institution, the practice of eugenics, and the implementation of service delivery models based on the normalisation principle. The origins of these moments are largely located in Western contexts and their development in the South African context, with its particular racial colouration, is traced.

In chapter 4 significant practices in the education of intellectually disabled people are identified. Practices of exclusion, differentiation, special education and professionalisation in educational provision are examined. The South African context is considered as a highly racialised arena for the ordering of individuals for the education system. Practices of advocacy that adopt a human rights view are also identified in mainstreaming and inclusive education practices. This chapter contains a discussion of South African inclusive education policy that promotes inclusion of disabled learners in regular schools and a changing function for special schools.

The methodology of this study is set out in chapter 5, starting with a discussion of the connection between the theoretical framework of this study as the rationale for the choice of

Q-methodology. The Discourse Analytic (DA) school of Q is distinguished from the Scientific Study of Subjectivity (SSS) school and the DA variant is adopted in the current study. The method for this research project is described in detail including the research questions, the development of the research instrument, the selection of participants, the conducting of interviews, the statistical analysis and the analysis and interpretation of the data. This is followed by a description of the ethical procedures followed, noting especially considerations for a vulnerable group, that is, intellectually disabled adults. This chapter is concluded with a brief description of the study area.

The results of these studies are presented in response to the first two research questions in chapter 6 (representation) and chapter 7 (educational practice). The findings show that there are a multiplicity of discourses of representation in which the understanding of competence, organic impairment and difference are variously patterned. The relative significance of social inclusion, spirituality, autonomy and the family are also noted. Ultimately four major discourses of intellectual disability were identified and these were named as:
A4.1: Interactive discourse
A4.2: Social model/ human rights discourse
A4.3: Medical model/religious discourse
A4.4: Community/religious discourse
Six discourses of educational practice were identified for Q-study B and these were named:
B1: Inclusion is a human right.
B2: Special needs require special provision.
B3: Inclusive education is a dream of the future.
B4: No expense should be spared in providing the highest level of special education.
B5: Effective education must be tailored to the child’s needs.
B6: Special education keeps children safe.

The third research question concerns the effects of the discourses and requires a closer examination of the discursive context in which these specific discourses of representation and educational practice occur, as well as an examination of the relationship between them. This task is undertaken in chapter 8 where representational discourse is related to the theoretical framework and thematic categories identified in chapters 3 and 6. Similarly educational discourse is reviewed with respect to educational practices highlighted in chapter 4 and the thematic categories used in presentation of the findings in chapter 7. The key areas that are identified concern the operation of power exercised in professional practice and the imbrication of religious discourse within representation of pastoral power. The deployment of human rights to different educational ends is also noted and the figuring of family and community in these discourses is highlighted. The construction of impairment and the intellectually disabled subject is explored in the final section of this chapter.

In chapter 9 I conclude my dissertation by reviewing some of the methodological insights gained in the course of this research project. Future research directions are identified regarding the ways in which an individual works on him- or herself to become an intellectually disabled subject and the possibilities for resistance that can be exploited in this process. It is noted that education policy might not always have its intended effects and critical examination of policy might assist in teasing out these effects. Finally, in arguing for a theory of (poss)ability, I make a plea for ensuring that the difficult material conditions and everyday life circumstances of intellectually disabled people should not be neglected within discourse-based research.

CHAPTER 2: THEORETICAL FRAMEWORK: POST-STRUCTURALIST CRITICAL DISABILITY STUDIES

> What varieties of men and women now prevail in this society and in this period? And what varieties are coming to prevail? In what ways are they selected and formed, liberated and repressed, made sensitive and blunted? What kinds of 'human nature' are revealed in the conduct and character we observe in this society in this period? And what is the meaning for 'human nature' of each and every feature of the society we are examining? (Wright Mills, 1959/2000, p. 7)

The education of intellectually disabled people has, for the most part, been constructed as a problem requiring the development of a distinct discipline of Special Education in contemporary education systems. Within this discipline intellectual disability is viewed as an individual, organically based condition that requires a specialised response in terms of curriculum, location of education and professional expertise. Drawing on a medical model of disability, intellectual disability is understood as a naturally occurring phenomenon that can be best explained through the application of positivist scientific method. The progressive accumulation of knowledge about the true nature of intellectual disability can then inform the specialised approaches that constitute professional special educational knowledge (Thomas & Loxley, 2001).

In this thesis, I adopt an alternative approach to the education of intellectually disabled people. I do not examine the truth claims made within medical and special educational disciplines as to what the causes of intellectual disability are, what the means of diagnosis are, and what treatments are most effective. My focus is not on intellectual disability as an object of medical knowledge but rather on how it emerges as a discursive object and imposes a certain identity and truth on those who are so classified. Following Wright Mills in the opening quotation, I ask what variety of human beings are being formed within the practice of education, as it constructs intellectual disability in the particular form and shape that it is understood in contemporary discourses.

In order to carry out such an investigation, I adopt a framework aligned with the academic discipline of disability studies, arising from the resistance of disabled people to being defined and excluded by rigid applications of a medical model of disability. However, the notion of disability studies as a single coherent field must be dispelled from the outset as the label covers a range of approaches (Shakespeare, 2006). I adopt a critical disability studies approach (Tremain, 2006) that draws on post-structuralist theorising. In so doing I base my analysis on an examination of the nexus of power and knowledge that constructs the intellectually disabled subject within educational practice.

In explicating my theoretical framework within this chapter, my starting point is a brief overview of the social model of disability, which has informed the disability rights movement and has had a significant impact on the academic field of disability studies. I shall then offer a critique of this model with particular emphasis on its application to intellectual disability. This will entail highlighting some of the problems that a simplistic binary model of impairment (as biological) and disability (as social) poses and will lead into an argument for collapsing this binary within a discursive understanding of disability. I shall then explore the post-structuralist conceptions of power and government of the population as they relate to the intellectually disabled subject. In recognition of the centrality of discourse in a post-structuralist theoretical framework, I shall offer a clarification of the understanding of discourse adopted in this study. In the subsequent section, I consider the criticism of this turn to discourse as eroding possibilities for resistance. At this point, I offer a critical discussion of disability activism and human rights from a post-structural perspective. Noting that feminism and critical disability studies have many common concerns I shall conclude this theoretical chapter by examining useful connections between the two disciplines.

The Social Model of Disability

The social model of disability has its roots in a rejection by disabled people of their segregation into institutions, and a call for their full participation in society by the Union of the Physically Impaired Against Segregation (UPIAS) (1974/5). The model was an attempt to move away from an understanding based in biological determinism that justified the restriction of participation of disabled people in the community on the grounds of their perceived physical deficit. It was argued that this resulted in inhumane and abusive practices such as institutionalisation and “systematically shunting disabled people into apartheid-like facilities” (Finkelstein, 2005, p. 1). With the growth of technology, many of the physical problems associated with impairment could be overcome. The need for segregated facilities was therefore reduced, but was nonetheless continued as a form of oppression of disabled people as a minority group. Institutions were viewed as a source of oppressive practices that were replicated in society as a whole:

> Physically impaired people will never be fully accepted in ordinary society while segregated institutions continue to exist, if only because their [segregated institutions] unnecessary survival today reinforces out of date attitudes and prejudices. (UPIAS, 1974/5, ¶ 13)

UPIAS also firmly rejected the biomedical tradition of dealing with disability on the grounds that it granted power over the lives of disabled people to medical professionals:

> But the imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly … Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, taking decisions behind our backs. (UPIAS, 1974/5, ¶ 14)

An activist stance was adopted where disabled people strongly asserted their leading role in liberation from their oppressive exclusion and insisted that professionals were only relevant insofar as “they build on and encourage the self-help and activity of disabled people themselves.” (UPIAS, 1974/5, ¶16). The major grievances of this group were the segregation of disabled people, the medicalisation of disability and the deployment of charitable discourses around disability. They sought to refigure disability as a public, rather than a purely personal, issue and laid the foundations for what came to be known as the social model of disability.

The social model of disability makes a firm distinction between impairment and disability. The Disabled People’s International definition is cited by Oliver (1996):

> IMPAIRMENT: is the functional limitation within the individual caused by physical, mental or sensory impairment.
> DISABILITY: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. (p. 31)

The distinction is made between the limitations that people with physical impairments face arising from the physical impairment itself, as against barriers generated by an uncaring and oppressive society. The logical response within this understanding is collective political action of disabled people. There is a rejection of medicalisation of disability since it is not a disease but rather a social condition, the treatment of which the medical profession has arrogated to themselves (Oliver, 1990). In this configuration, the disabled person is transformed from an object of charity — who must be both deserving and grateful — to an active agent with rights that impose obligations on the wider society. In its drive to be inclusive, the social model incorporated all impairment types, including intellectual disability (Chappell, Goodley, & Lawthorn, 2001).

This “big idea” (Hasler, 1993, cited in Shakespeare & Watson, 2002, p. 3) of the disability movement then opened the way for collective action to address societal barriers to participation. The recognition of the common experience of disabling environments validated and connected the experiences of disabled people:

> The social model of disability has given us [disabled people] the language to describe our experiences of discrimination and prejudice and has been as liberating for disabled people as feminism has been for women. (Morris, 2001, p. 4)

As has been noted by even its strongest proponents, the social model of disability was never intended to be an all-embracing social theory but rather a political intervention that provided a basis for collective action (Shakespeare, 2006). In this respect “The disability movement was following a well-established path of de-naturalising forms of social oppression, demonstrating that what was thought throughout history to be natural was actually a product of specific social relations and ways of thinking” (Shakespeare, 2006, p. 30). The academic partner of disability activism, disability studies, reflects to a large degree the strongly activist force of the social model. However, the conception of disability and the form that activism or resistance should take varies considerably. I shall discuss some of the differences below.

Disability Studies

The field of disability studies, while a relatively new one, has developed considerably since its early formulation based on the social model of disability. Meekosha (2004) distinguishes between two major strands of disability studies, the one arising from the United Kingdom (UK) and the other from the United States of America (USA) and notes that these variants are grounded in the different intellectual/political milieus of these countries. She traces a development of disability studies similar to that of feminist scholarship:

> Women’s studies also demonstrate culturally-determined stands — where the British involvement has focused more on issues of equality in political and material participation (Phillips, 1993, 1995). US scholars have been more concerned with issues of psychology, identity, personal affirmation and moral development. (p. 722)

According to Meekosha (2004), the origins of disability studies in the USA were concerned largely with processes of the creation of ‘deviance’ and its critique was focused on these processes. There is a strong tradition of disability studies in the humanities, embracing literary studies, history, philosophy and cultural studies. The UK strand, on the other hand, reflects the “close relation between sociology, social policy and the politics of the welfare state in Britain" (p. 729). It was developed more in the context of social services within a radical critique of a social welfare state and a broader liberation struggle based on a class analysis of oppression. The USA form of resistance can be viewed more as an expressive form that focuses on identity and every day power relations, whereas the UK activism is more instrumental with its emphasis in the broader economic and political spheres (Stammers, 1999).

However, it is the British variant of the social model that has been drawn upon in South Africa as a framework for social change for disabled people. This is specifically spelt out in the Integrated National Disability Strategy, which sets the tone for all disability related policy:

> The social model is based on the belief that the circumstances of people with disabilities and the discrimination they face are socially created phenomena and have little to do with the impairments of disabled people. The disability rights movement believes, therefore, that the 'cure' to the 'problem' of disability lies in restructuring society … The social model therefore emphasises two things: the shortcomings of society in respect of disability, and the abilities and capabilities of people with disabilities themselves. (Office of the Deputy President, 1997, p.11)

In the South African academic context disability studies is still in its infancy. However, the British variant is evidenced more strongly, within the only disability studies programme in the country at the University of Cape Town. This programme describes disability studies as:

> an independent academic field within health and social sciences. Disability studies aims to build a new body of knowledge that sees disability as social oppression where otherness, discrimination, systematic exclusion and oppression are the appropriate foci of critical analysis. (Lorenzo, Toni, & Priestley, 2006)

At the same time, there is recognition that a uniquely South African and African understanding of disability needs to be developed. Lorenzo et al (2006) stress the importance of research directed at understanding the particular forms of disability oppression evident in the South African context. Given the dominance of the British variant in the South African context of political action and the discipline of disability studies, I shall expand on the British model below.

Oliver (1996) expands on the disability/impairment distinction in his defence of the social model. He rejects a causal link between disability and impairment since disability is wholly socially created, while impairment is purely biological. This allows him to distinguish between those aspects of the disabled person's experience that are amenable to medical and therapeutic attention (impairment) and those aspects that call for a political response (disability). The physical reality of the impairment is viewed as an essentially unimportant biological attribute of the individual that is stigmatised through negative labelling practices and the tyranny of the norm that underpins "the assumption that disabled people want to achieve this normality" (p. 34). He posits the need for "the development of a politics of difference" (p. 35) that resists normalising tendencies in pursuit of a positive identity. This identity is constructed not on a common experience of impairment but rather on the shared oppression that causes the disablement of people with impairments in society. In order to move towards this politics, disabled people themselves must seek a common identity based on disability, rather than impairment. This identity can be achieved through greater control of services and by research that is directed toward disability. Personal experiences arising from different impairments are minimised in "a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or professional treatment" (p. 39).

Within the British variant of the social model expressed by Oliver (1996), a strongly historical materialist conceptualisation is adopted. He rejects post-modernist thinking on the grounds that it locates oppression in "society's hatred of us [disabled people]" (p. 41). He maintains that post-modernism does not therefore challenge the *status quo* and argues that "our [disabled people's] oppression is ultimately due to our continued exclusion from the processes of production and not because of society's hatred" (p. 41).

Abberley (1997) similarly adopts a materialist analysis but argues that impairment, and not only disability, is a social phenomenon in some respects. In his discussion of the concept of oppression with respect to disability, he bases his argument on three premises:

1. Disabled people are an inferior group in society.
2. The disadvantages they suffer are related to ideologies that perpetuate this situation, rather than natural ways of the world.
3. Somebody is benefiting from this state of affairs.

For disabled people the biological difference leads to justificatory oppressive theories and the naturalisation of impairment blocks the development of a political consciousness. In contrast to Oliver's view of impairment as purely biological, Abberley views it as social in its origin, caused within relations of production and consumption and by economic inequality. However, he maintains a firm distinction between biological "reality" and social processes, since his explanations are:

> directed at the explication of the social origin of what are material and biological phenomena and should be understood not as dissolving these material elements into attitudes or ideas but rather as pointing to the inextricable and essential social elements in what constitutes a material base for ideological phenomena. (Abberley, 1997, p. 170)

Thus impairment itself is viewed as a purely physical, organic deficit within a theory of oppression that makes the "claim that historically specific categories of 'disabled people' were constituted as a product of the development of capitalism and its concern with the compulsion to work" (p. 175). The physical reality of impairment enables the construction of social categories of disabled people. Resistance to this oppressive categorisation entails the participation of disabled people themselves as researchers or in setting the research agenda (Shakespeare, 2006). This is strongly evidenced in the South African disability studies programme, which has as an explicit aim the development of a cadre of disabled researchers who will be able to further the disability agenda (Lorenzo et al., 2006).

The application of the social model as a tool for activism and a basis for disability studies has been unsatisfactory for people with intellectual disabilities (Chappell, 1997; Chappell, et al., 2001; Goodley, 2001; McClimens, 2002). In part, this lack of success is due to the incomplete application of the social model to intellectual disability. Chappell (1997) notes that "learning disability" (the British term for what is termed intellectual disability in the South African context) is neglected within the social model. She argues that it needs to be considered both in the pursuit of inclusivity of the model and for theoretical coherence. Within the disability studies movement intellectual disability is viewed as a late and tenuous addition. In this sense intellectual disability is marginalised from a social model account that emphasises a collective experience of disability and a united front in facing the oppression of a disabling society. Goodley (2004) notes that this is more evident in the UK version of disability studies than in the USA where "mental retardation" (the common American term in use) was conceived of as a social construction in the early days of disability studies.

In the light of these reservations, I shall adopt a disabilities studies perspective that critiques the social model while retaining an emancipatory intention. In so doing, I begin to take up the challenge posed by Goodley (2001):

> The aim now is to move from the social model of disability to mutually inclusive social theories of disability and impairment that are open and inclusive to people who have been labeled as having ‘learning difficulties’. (p. 225)

A *critical* disability studies adopts a discursive view of disability as constructed through social relations. It is an interdisciplinary pursuit that is concerned with issues such as identity, education, representation and sexuality (Ware, 2001). It departs from earlier versions of disability studies in a reworking of the binary between impairment and disability as articulated in the social model of disability, and frames impairment itself as part of the discursive space (Tremain, 2006). However, the emancipatory project that informs the social model is retained:

> Disability theorists ought, however, to assess the value and merit of these theoretical contributions (arising from the social model) in terms of the extent to which, and even whether, they can improve the circumstances of disabled people’s lives. After all, disability studies is married (for better or for worse) to the movement for the emancipation of disabled people.(Hughes, 2005, p.79)

This implies that an adequate theory of disability should include a recognition of the continued oppression of disabled people and acknowledge the need for political action to address inhumane material conditions. It is essential therefore that the participation and views of disabled people are an integral part of theorising and researching disability as part of this political agenda (Reid & Knight, 2006). It is for this reason that the views of intellectually disabled people were sought in the current study (see chapter 5).

I adopt a post-structuralist framework within critical disability studies as it has been noted as a rich though underutilised approach (Goodley & Rapley, 2006; Hughes, 2005; Tremain, 2005). The areas of focus are a) the impairment/disability binary, b) the operation of power, c) governing the population, d) the nature of discourse, e) the possibilities for resistance, and f) feminist disability studies. Each of these aspects is discussed below.

The Impairment/Disability Binary

Hughes and Paterson (1997) find the binary distinction between impairment and disability within the social model untenable and note that its effect is to concede “the body to medicine and understand impairment in terms of medical discourse” (p. 326). In this sense there is “a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self" (p. 329).

This tendency is reflected in the disability studies literature on intellectual disability where there is a tacit acceptance that intellectual impairment is naturalised (Rapley, 2004). However, what remains underexplored is the specific nature of impairment in intellectual disability. Is this impairment located in the mind or in the brain? Does it have biological correlates and how could these correlates be identified and measured? I shall explore some of these issues further in chapter 3. For the moment, suffice it to say that rather than trouble with marking the divide between the impairment and the disability, there has been a tendency to focus on the impairment rather than the disability in understanding intellectual disability. Goodley (2001) notes a reluctance to accept the fundamentally social nature of intellectual disability within the social model and a persistent view of intellectual disability as a naturalised impairment. Impairment is constructed as "a stable and oppositional category to 'normalcy'" (Goodley & Roets, 2008, p. 244). As long as the impairment remains untheorised, it remains personal and the political dimension of intellectual disability is driven underground.

Hughes and Paterson (1997) argue for a social understanding of impairment that will collapse the disability/impairment dualism in much the same way that feminist scholarship has sought to undo the sex/gender binary. I shall make use of insights from post-structuralist feminist theory, regarding the sex/gender distinction to begin theorising intellectual impairment.

Perhaps the most fundamental convergence between feminism and disability studies has been the recognition that bodies are constructed in certain ways with ensuing power relations. The distinction made between sex and gender in the feminist movement and between disability and impairment in the disability movement both attempt to distinguish between physical bodies and social arrangements. Where disability rights activists distinguished between *impairment* as a physical deficit and *disability* as social barrier, the early feminists made the distinction between *sex* as a natural category and *gender* as culturally specific and socially constructed. The sex/gender binary was recognised as problematic in the early phases of the feminist movement but was found to be too useful a tool in tackling biological determinist accounts of sex differences to be easily abandoned

(Tremain, 2006). However, this expediency came at the cost of conceding physical sex to the domains of medical and biological explanations.

A post-structuralist analysis of sex and gender gained currency by referring to an analysis of the relationship between sex and sexuality in Foucault’s *History of Sexuality: Vol.1.* (1976/1998). Here the argument is made that physical, naturalised and anatomical sex should not be seen as prior to or causal of configurations of sexuality. Rather it is sexuality that groups together these anatomical elements into a configuration that we then come to recognise as sex:

> the notion of “sex” made it possible to group together, in an artificial unity, anatomical elements, biological functions, conducts, sensations, and pleasures, and it enabled one to make use of this fictitious unity as a causal principle, an omnipresent meaning, a secret to be discovered everywhere.” (Foucault, 1976/1998, p. 154)

Foucault further argues that it is not sex that is the precursor to the operation of sexuality, but rather it is sexuality which inscribes sex on bodies, generating a power that is productive of possible ways of being and doing and that forbids others.

Within such an understanding of sexuality, Tremain (2006), drawing on Butler, concludes that sex differences cannot be seen as anatomical but rather they are a function of discursive practices that depict sex as a gendered category:

> For what counts as ‘sex’ is formed through a series of contestations over the criteria used to distinguish between two natural sexes which are alleged to be mutually exclusive. (Tremain, 2006)

This has important implications for the issue of impairment in disability studies. The parallels are obvious. A politically useful distinction between natural impairment and socially constructed disability is formulated in an attempt to move away from the biological determinism of impairment. In so doing the terrain of impairment is conceded to a biomedical discourse. Impairment is figured as prior to disability as a naturally occurring entity. The effect of this deployment of bio-power (see discussion of power below) is to construct impairment as a pre-discursive, natural entity, which serves to “legitimise the disciplinary regime that generated it in the first place” (Tremain, 2006, p. 43).

In similar fashion to the collapsing of the sex/gender distinction, the challenge for post-structuralist critiques of disability studies is to recognise impairment and disability as one and the same thing. Tremain (2006) argues therefore that impairment should no longer be portrayed as a biological entity:

> Instead, those allegedly ‘real’ impairments must now be identified as the incorporated constructs of disciplinary knowledge/power that they are. As *effects* of an historically specific political discourse — bio-power -— impairments are materialized as unitary and universal attributes of subjects through the iteration and reiteration of rather culturally specific regulatory norms and ideals about human function and structure, competency, intelligence and ability. (p. 42)

Hughes and Paterson (1997) draw on Butler in their understanding of impairment as:

> a product of discursive practices; like sex it is an effect, rather than an origin, a performance rather than an essence. The re-iterative power of discourse perfects the performance so that the body not only becomes the materialisation of its diagnostic label but also its own set of constraints and regulations. In this post-structuralist view, impairment is no longer a biological fact, but a discursive product. (p. 333)

This identification of disability with impairment differs greatly from a biomedical, positivist view of disability. While the positivist view is that both impairment and disability are biological, the post-structuralist perspective sees them both as discursively constructed. In this light the distinction between disability and impairment is collapsed to enable “a view of the world which does not separate impairment and disability as binary oppositions but throws both into the dynamic world of discourse and practice” (Goodley & Rapley, 2006, p. 139)

Thus the understanding of impairment in this thesis reflects a discursively constructed entity. This is not to say that I object to, deny or minimise biological data that enhances an understanding of intellectual disability. Wilson (1999) makes an argument for feminist theory to engage more closely with biological data in order to enrich the understanding of the body. She critiques the current tendency of feminist analysis to seal off the biological as “reductive materiality stripped of the animating effects of culture and sociality” (Wilson, 2004, p. 3) and argues for establishing a continuity, rather than an opposition, between the biological and the cultural. This continuity, she describes as a conversation or communication between what is internal and what is external to the body. Thus a hysterical conversion of psychic conflict into bodily symptoms, such as pain or paralysis, provides an example of social and emotional experience manifesting upon the physical, biological body. What are the mechanisms that enable this conversion to occur? In terms of disability studies such a line of questioning would require a reformulation not only of the ways in which impairment creates disability but also allows for a conception of a counter-communication where disability creates impairment. Should such mechanisms be clearly identified, the static nature of impairment as the inert biological given becomes transformed into a more fluid understanding of impairment. This offers an intriguing avenue of exploration for disability studies, which has been particularly virulent in its rejection of biological explanations that are considered the domain of biomedical models, but it will not be specifically followed in this thesis.

The Operation of Power

An additional difficulty of the social model lies in a rigid application of an historical materialist analysis as noted above and a rejection of post-modernist theorising as descriptive rather than explanatory (Abberley, 1997; Oliver, 1996). While the value of a Marxist analysis is recognised in explaining the operation of exclusion and oppression, it restricts the understanding of power. As Hughes (2005) notes:

> The Marxist tradition that has dominated disability studies in the United Kingdom promotes a view of power that construes it as unitary, centralized and primarily coercive. (p. 81)

Tremain (2006) notes that the post-structuralist theorising of Michel Foucault has been underutilised in disability studies relative to its use within feminism, gay and lesbian studies, post-colonialism and other what she terms “oppositional discourses” (p. 32). She attributes this to the conception of power as juridical underlying the social model as a basis for disability studies, especially in the British variant. Juridical power is described by Foucault (1976/1998) as deductive and “essentially a right of seizure: of things, time, bodies, and ultimately life itself” (p. 136). Such power is the possession of individuals through inalienable right, and functions through “prohibition, censorship and denial” (p. 10). However, in his analysis of sexuality, Foucault argues that the uses of juridical power are limited and have been displaced by new forms of power that do not repress, prohibit and deduce action, but rather act to incite, order and produce forms of conduct. This is “a power bent on generating forces, making them grow, and ordering them, rather than one dedicated to impeding them or making them submit” (Foucault, 1976/1998, p. 136). In the discussion below, I shall draw on the work of Michel Foucault, specifically in terms of disciplinary power, bio-power and the construction of the intellectually disabled subject.

Disciplinary Power

In his work *Discipline and Punish*, Foucault (1975/1995) explores the transition of punishment from a spectacle of torture acting upon the body to a more hidden part of a larger penal process. He rejects a view of this process as an enlightened progression from excessive power, displayed in the application of brute force on the body of the criminal, to more humane forms of punishment. Rather he traces the development of a more effective and comprehensive exercise of power through the progressive development of knowledge about the individual in the form of disciplinary power.

Foucault (1975/1995) traces the move away from punishment, as revenge of the sovereign in the late eighteenth and early nineteenth centuries, toward a new form of punishment that does not serve to punish the offence alone but also to “supervise the individual, to neutralize his dangerous state of mind, to alter his criminal tendencies, and to continue even when this change has been achieved” (p. 18). The nature of the crime came under scrutiny: “It is no longer simply ‘Who committed it?’, but: ‘How can we assign the causal processes that produced it? Where did it originate in the author himself? Instinct, unconscious, environment, heredity?’” (Foucault, 1975/1995, p. 19). These questions required an investigation of the individual outside of the juridical process. What are their intentions and habits, so that “experts might come to know and predict the behaviours of deviant subjects” (Hook, 2007, p. 12). In so doing the object of punishment moved from the body to the soul of the criminal, constituting a form of power exercised over a much wider range of humankind than the criminal:

> It would be wrong to say that the soul is an illusion, or an ideological effect. On the contrary it exists, it has a reality, it is produced permanently around, on, within the body by the functioning of a power that is exercised on those punished and in a more general way on those one supervises, trains and corrects. (Foucault, 1975/1995, p. 29)

Ultimately Foucault argues that all the human sciences have their roots in the structuring of punishment as a concern with improvement of individuals. As such they are part of the mechanisms of disciplinary power.

Foucault (1975/1995) traces the operation of disciplinary power through the production of “docile bodies” wherein bodies are distributed according to their value in the system of production and controlled through the careful arrangement of activity, time and the combined application of bodies in a unitary force. Within the classroom pupils can be ordered and become known along a multitude of dimensions: “Thus, the classroom would form a single great table with many different entries, under the scrupulously ‘classificatory eye’ of the master” (Foucault, 1975/1995, p. 147)

Within such a structure each individual must be assigned his or her own place, in terms of a certain rank within the order. This “art of distributions” (Foucault, 1975/1995, p. 141) can result in physical divisions (such as those of asylums or, in the case of intellectual disability, special schools and institutions) or the enclosure of the individual in conceptual spaces such as the category of “severely mentally handicapped”. At the same time pupils are subject to a rigid training system that controls both time and activity, the purpose of which is to make the individual knowable and useful in production. It is within this system that intellectual disability becomes set apart as a problem to be solved (see chapter 4).

The means of correct training constitutes a further play of power in the creation of docile bodies. The instruments of correct training, namely, hierarchical observation, normalising judgement and the examination are all evident in the operation of mass education. Through hierarchical observation, as manifested in the architecture as well as in the disciplinary arrangements of the school, all pupils are made visible. For example, classrooms located along a passageway make for easy visibility. The pupil then becomes subject to surveillance by a supervisory system under the direction of the teacher who may delegate supervision to other pupils where necessary (Foucault, 1975/1995). Surveillance is not only a physical but also a psychic exercise that requires “maximal and penetrating knowledge about the subject” (Hook, 2007, p. 30). Hence, detailed assessments and recordkeeping also serve purposes of surveillance.

The normalising judgement is the form of punishment favoured within disciplinary power. It has as its purpose the comparison of the individual to the norm and allows individuals to be differentiated in terms of their relation to the average. Since this judgement measures in quantitative terms, it designates a value to the person’s abilities or nature. It specifies the conformity that needs to be achieved as well as “traces the limit that will define difference in relation to all other differences, the external frontier of the abnormal” (Foucault, 1975/1995, p. 183). In so doing it is not only the individual who is placed within a hierarchy but also a comparative structure is established as a backdrop to the individual ranking. In this way the individual is both a subject of their own placement within the ranking and an object of knowledge for further differentiation and normalisation that delineates the boundaries of the norm and the beginnings of deviance. Thus the practices that were developed in disciplinary contexts are preserved and are not confined to the control and rehabilitation of difficult individuals:

> The real goal of rehabilitative and punitive endeavours is thus not the complete elimination of deviances and regressions, but rather the tactical use, the strategic deployment of such problems as a means of justification for ever greater schedules of control and surveillance. (Hook, 2007, p. 39)

The diagnosis of intellectual disability is in itself based upon a normalising judgement. The following widely used definition of intellectual disability, from the *International Statistical Classification of Diseases and Related Health Problems Disabilities Tenth Revision* (ICD-10) developed by the World Health Organization (WHO), illustrates this point:

> A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition. (WHO, 2007)

In such a way the intellectually disabled person is compared to the norms of intellectual, language, motor and social abilities, differentiated from the average, found to be lacking in value and ultimately cast beyond the norm into the realm of the abnormal. This process does not only impact on the intellectually disabled but serves to illustrate for all the centrality of the norm, since: “The Normal is established as the principle of coercion in teaching with the introduction of standardised teaching” (Foucault, 1975/1995, p. 184).

The examination is a technique that combines the strategies of hierarchical observation and normalising judgement. It is usually highly ritualised and invested with the trappings of power (Hook, 2007). The examination is a measure of potentiality – the subject’s future capability. It translates the single act into a stable trait and a particular way of being. Rembis (2008) explores the application of the examination in records of intelligence testing in an early twentieth century American setting. He concludes that, in this context, it was the examination ritual with the IQ test as instrument that constructed intellectual impairment as a means to deal with young women who were deemed for whatever reason to be sexually threatening.

The examination can be likened to the "assessment", which is described as follows in the ICD- 10:

> Degrees of mental retardation are conventionally estimated by standardized intelligence tests. These can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of mental retardation. The diagnosis will also depend on the overall assessment of intellectual functioning by a skilled diagnostician. (WHO, 2007)

Rose (1998a) describes the process of differentiating between individuals as a progressive project of disciplining difference. The capacities, skills and potentialities of individuals are examined and described in detail in an effort to sort humans into the type of regime they would best be suited for and where they would contribute most and disrupt least the processes of production. In terms of intellectual disability, intelligence tests and developmental scales served both to test individuals relative to the norm and construct the norm through testing. These tests enabled a much finer distinction of classes of intellectually disabled children and allowed for the prescription of educational practices. This will be discussed more fully in chapter 4.

While the process described by the WHO has all the trappings of a scientific and objective gathering of information about the individual, Foucault's description of the examination casts it in an entirely different light, which has not been fully explored with respect to intellectual disability. This is where power and knowledge are manifest as one:

> People write the history of experiments on those born blind, on wolf-children or under hypnosis. But who will write the more general, more fluid, but also more determinant history of the 'examination' – its rituals, its play of questions and answers, its systems for marking and classification? For in this slender technique are to be found a whole domain of knowledge, a whole type of power. (Foucault, 1975/1995, p. 185)

The operation of disciplinary power forms part of a mechanics of power that operates at the level of individual bodies. However, with the development of new forms of state government that took population as its target, it comes to be aligned with the knowledge of populations in a configuration of bio-power.

Bio-power

In the final chapter of The *History of Sexuality: Vol. 1.* Foucault (1976/1998) crystallises a bipolar concept of bio-power in which the one pole focuses on the body as individual anatomy, "an *anatamo-politics of the human body*" (p. 139), and the other pole operates at the level of the body as species with its biological patterns of morbidity, reproduction and other mechanisms of life. In so doing he forges a link between the techniques of power operational on the body to the exercise of power at a broader social level — a linking of the micro and macro levels of power. Power over the anatomical body is exercised through disciplinary technologies that configure the body as a productive machine. Power over the body as species is exercised through the description and regulation of the population through the development of sciences such as demography and economics. The population is described in terms of numbers to be used in political and administrative debates and decisions (Rose, 1990).

The operation of bio-power is more dependent on the norm than on the exercise of juridical law:

> It is no longer a matter of bringing death into play in the field of sovereignty, but of distributing the living in the domain of value and utility. Such a power has to qualify, measure, appraise, and hierarchize, rather than display itself in its murderous splendor. (Foucault, 1976/1998, p. 144)

This new form of power over the biological species emerged and embedded itself within disciplinary power in the second half of the eighteenth century. It differs from disciplinary power in that it deals with the population "as political problem, as a problem that is at once scientific and political, as a biological problem and as power's problem" (Foucault, 2003, p. 245). Through the use of statistics, forecasts, predictions and estimates, it targets the unpredictable and establishes an equilibrium based on averages that regulate these random events, bringing them under control of government. These forms of power can be distinguished from each other as different series of concepts:

1. Disciplinary power — body — organism — discipline — institutions (organo-discipline).
2. Bio-power — population — biological processes — regulatory mechanisms — State (bio-regulation) (Foucault, 2003, p. 250).

Medicine can be understood in relation to these forms of power as having an application to both the anatomical body of the patient and the regulation of the population through controls over diet, sexuality, hygiene and a whole range of behaviours. The element that circulates between these two is the norm. The norm can be applied at the level of an individual body as a disciplinary technology and at the level of the species as a mechanism of regulating the population. A normalising society covers both the biological and the organic since the norms that exist at different levels of power operation intersect with each other.

In the case of intellectual disability, at the level of the anatomical body, procedures of assessment, diagnosis and rehabilitation are instituted (see chapter 3). The limited success in making the intellectually disabled person conform to the norm constitutes intellectual disability as a problem to be solved through the application of therapeutic technologies in the form of specialised training or rehabilitation (see chapter 4). At the level of the biological species, the distribution around the norm is effected through the normal distribution curve used in the application of intelligence testing, a normalising process that informs the decisions of the authorities.

The norms that are established within bio-power have come to be understood as the essence of humanity and therefore as the *right* of the individual:

> The “right” to life, to one’s body, to health, to happiness, to the satisfaction of one’s needs … this “right” … was the political response to all these new procedures of power which did not derive, either, from the traditional right of sovereignty. (Foucault, 1976/1998, p. 145)

Bio-power complements the exercise of power over the individual body within the administration of the state in a developing practice of governmentality that constructs subjects in such a way as to make them governable.

Governing the Population

The conception of governmentality is central to Foucault’s theorising of power as the means by which the individual is made governable as a useful and productive member of the state. By the term governmentality he refers to:

> The ensemble formed by the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power, which has as its target population, as its principal form of knowledge political economy, and as its essential technical means apparatuses of security. (Foucault, 2002, pp. 219-220).

The population is figured not as a group of individuals but rather as an entity in and of itself with its own specific birth, death and fertility rates, and a range of other variables, that are to be understood through the science of statistics (Foucault, 1976/1998, discussed further in chapter 3). With this conception of population, the economy assumes reality as the specific deployment of resources for the well-being of the population as a whole. The economy is that “specific sector of reality” (Foucault, 2002, p. 219) that concerns the relationships between populations and the material world. Political economy then is the science and technique of intervention of government within this domain of truth.

Apparatuses of security are the technical means of governmentality as they form the link between power exercised at the individual level and that exercised by the State or governments. In this respect governmentality represents an extension of Foucault’s efforts to link the micro-physics of power operating on individual subjects to a macro-physical level of the government of nations, states and populations (Hook, 2007). Fundamental to the concept of governmentality is the science of police, a term Foucault used to delineate practices that order and administer a population in such a way as to maximise the development of a sound political economy (Dean, 1994).

In order to govern there must be a knowledge of what it is to be governed. This knowledge is not merely a knowledge of existing objects, it is rather:

> a positive knowledge of the domain to be governed, a way of rendering it into thought, so that it can be analysed, evaluated, its ills diagnosed and remedies prescribed. Such representation has two significant aspects: the articulation of languages to *describe* the objects of government and the invention of devices to *inscribe* it. (Rose, 1998a, p. 70)

In this sense the logic of governmentality creates the very objects that it seeks to govern through their elaborate description with reference to the norm. Thus, governmentality refers to a complex deployment of power and knowledge such that it establishes a taken -for -granted truth as the rational basis for government of the population. To this end the science of police is complemented by the operation of pastoral power (see discussion below) that renders the individual knowable, linking the technology of government of populations to the government of the self.

The operation of governmentality does not merely *describe* an external reality but rather it *creates* objects that are amenable to government. As Tremain (2005) puts it, with respect to disability, “the category of impairment emerged and, in many respects, persists in order to legitimize the governmental practices that generated it in the first place” (p. 11). In the present discussion, the construction of the intellectually disabled subject as a *product of* and a *problem for* education will be explored in greater detail below. The central role of the medical and psychological disciplines in delineating the object of intellectual disability and associated practices is foregrounded in this discussion. I shall identify three aspects that are evident in the government of populations that are essential to the understanding of the construction of the intellectually disabled subject of medical and educational intervention as a problem for the education system. These are a) the medical gaze, b) pastoral power, and c) the development of expertise.

The Medical Gaze

In one of his earliest works, *The Birth of the Clinic*, Foucault (1963/2003) traces the development of the practice of clinical medicine. In the early eighteenth century, disease could be viewed as a botanical entity – something to be classified, observed and known in its natural state as far as possible. Its effects would then be known and predictable, bearing in mind that the body in which it became manifest might obscure some of these effects. From the late eighteenth century a series of shifts occurred in which the body became commensurate with disease; disease was inserted within the individual body. The health of the body came to be seen as relative to a norm (rather than as the overall vitality of the organism) and was viewed through the normal/pathological prism. The power to make the determination of normality was invested in the authorised professional who was controlled by various regulatory structures. The doctor, through observation of the patient, was seen as able to penetrate the body's secrets just by looking, and to diagnose and to speak wisely about its treatment. This constituted the medical gaze that assumed the status of knowledge of truth about the health of the individual.

However, Foucault argues that this gaze, far from revealing what is already there, actually serves to construct the human body in certain ways and to regulate its actions through the concern with the norm and the desirable state of health that individuals should achieve. Rose (1998b) notes the development of lines of visibility, that “arranged bodies, spaces, gazes, inscriptions within a certain regime of light that sickness — and with it health — became relocated in a thoroughly empirical domain of observable events and mathematical regularities”(p. 61). It has been the task of clinical medicine to make the invisible visible through a variety of means, beginning with the bedside observation and including the detection of signs, such as pulse and temperature. The differences between individuals became regulated under the authoritative medical gaze of the physician. As long as the difference could be made visible it “makes the person stable through constructing a perceptual system, a way of rendering the mobile and confusing manifold of the sensible into a cognizable field" (Rose, 1998a, p. 106).

Intellectual disability posed its own particular difficulties in this respect as only the most severe forms could be detected in an uncomplicated manner in the body. However, with the advent of the need to classify and differentiate the feeble-minded from the norm and those more severely affected, a norm referenced mathematical solution was found in the intelligence test (see chapters 3 and 4). This tool expanded the authority of Psychology and granted to psychologists the authority to pronounce on the truth of intellectual disability (Rose, 1985).

Pastoral Power

In the operation of governmentality, individual apparatuses of power are exercised. I have noted above that the operation of police serves to administer bio-power in such a way as to maximise the state's controls over its citizens, through regulation of the relationships between individuals within a political economy.   This apparatus is complemented by a more individualised operation of pastoral power. Foucault (1979) traces this form of power to the Judaeo-Christian conception of the shepherd/pastor caring for his flock as an intermediary of a greater power or knowledge, typically God. Thus there is an unquestionable authority that comes to characterise his leadership.

The pastor gathers and guides the flock, assuring their health, safety and protection through a constant benevolent supervision. To fulfil this responsibility, the pastor needs to know "of the needs and deeds, the sins and wishes, *the contents of the soul*, of each member of the flock" (Hook, 2007, p. 238). The members of the flock, in return for this protection, must exhibit obedience, self-renunciation and personal submission. They must acquire the habits of confession to the pastoral representative as well as thorough self-examination, the outcome of which is a developed form of conscience in its subjects (Hook, 2007).

While this technique has its origins in the Christian tradition, it now serves as a tool for the creation of individuals within the modern state. In this changed strategy, pastoral power has as its object, not eternal salvation, but rather a good quality of life, health and security. In the shift toward a secular form of pastoral power, the officials who exercised this form of power multiplied to include those in the disciplines of Medicine, Welfare, and Psychology and even extended to within the family structure (Foucault, 1982).

At the same time, the objectives of pastoral power have changed to facilitate the exercise of bio-power by allowing for the links to be made between the totalising knowledge of the population and an analytical knowledge of the individual. The new form of pastoral guidance underpins caring treatment, motivated by a heart-felt duty or calling. Members of the disciplines act through a love for their charges, judiciously dispensing their expertise in the best interests of these individuals who need only to respond in the correct way to improve on themselves and attain a better quality of life (Hook, 2007). The effect of this power is critical in the creation of the subject:

> This form of power applies itself to immediate every day life which categorizes the individual, marks him *(sic)* by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word "subject": subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. (Foucault, 1982, p.781)

The double meaning of subject usefully encapsulates the dual processes of becoming a subject — the subject is created from without (subject to) by surveillance and discipline and from within (subject of) by confession and self-examination (Durrheim, 1997). The external process can be usefully described as *subjectification* where the individualising disciplinary knowledge locates the subject with respect to the norm and applies normalising techniques. The internalising process where the subject comes to understand themselves in terms of these notions is termed *subjectivisation* as a reflexive process (Hook, 2007). The interaction of these two processes can be detected in the application of psychological expertise in the assessment, diagnosis and treatment of intellectual disability.

The Development of Expertise

Rose (1998a) examines psychological expertise as a form of pastoral power for the production of governable subjects. He distinguishes expertise from professionalisation, as psychological expertise extends beyond the practice of the profession of psychology. Whereas professionalisation refers to the ways in which the experts of a particular discipline mark out their territory and establish a monopoly on the services that they provide, expertise operates in more diffuse ways. It coalesces an assemblage of techniques and strategies that are bound together more by pedagogy (in the form of text books, courses and credentials) than by a unifying theory. Psychological expertise has been particularly successful in attaching itself to forms of practice other than psychology – doctors, nurses, social workers, therapists and special educators draw upon this expertise freely in “reformulating their ways of explaining normality and pathology in psychological terms, giving their techniques a psychological coloration” (Rose, 1998a, p. 87).

This psychological gaze renders individuals calculable through the application of technology as exemplified in the test. While the intelligence test comes first to mind, special education and its therapeutic allies have at their disposal a plethora of tests of language skills, reading ability, sensorimotor integration, auditory analysis and synthesis, problem solving skills and so forth. Rose (1998a) argues that these technologies are neither measures of an objective quality of the individual nor are they merely administrative controlling practices. Rather the technologies and organisational practice of expertise *make* knowledge “a matter of technique, rooted in attempts to organize experience according to certain values” and in this manner “truth becomes effective to the extent that it is embodied in technique” (p. 89).

Expertise makes individual difference a technical matter that allows distinctions to be made between individuals not on the basis of prejudice, but according to objective criteria of the inherent worth of the individual. Subjectivity becomes visible to authority and guides its decision-making processes. In this way authority is legitimised as a practice exercised by those with knowledge of the subjects who are governed. Significantly, this is not only a rational authority but also an ethical one that acts in the best interests of individuals. The exercise of authority becomes a therapeutic practice based on knowledge of the inner nature of the subject. The relationship between the expert and client becomes a discipleship (Rose, 2007).

In terms of intellectual disability, the disciplines of Medicine, Special Education, Rehabilitation, and the Care industry as a whole circumscribe what it is to be intellectually disabled (see chapter 3 and 4). The relationship of the caring professions is couched in the “best interests of the child” within a loving relationship that carries the weight of expertise, in such a way as to obscure the operation of power (see chapter 8). The extent to which the intellectually disabled subject recognises him- or herself as a confessing, self-examining subject is not clear within the current study and relates to forms of resistance. This aspect remains underexplored and suggestions are made on how to advance this in future (see chapter 9).

I have argued against an understanding of impairment as a natural organic difference that exists prior to and distinct from the social ramifications of disability. The above discussion takes this understanding further through the use of post-structuralist theorising to understand impairment as both the product and the effect of power, since “Power thus operates through the production and deployment of discursive categories whereby individuals must recognise themselves and through which they must be recognised by others” (Durrheim, 1997, pp. 33-34). The operation of power is concealed from view through the notion of a natural object (impairment), scientific truth (disciplines of Psychology, Medicine, Special Education) and the need for care and protection (professional concern and love). In order to cast light on these processes, discourse analysis acts as “a practice that aims to unhinge and explicate the ideological/power relations that are established in the manner in which ‘objects’ are systematically represented and subjects are ‘interpellated’” (Durrheim, 1997, p. 33). It is for this reason that I undertake a discourse analysis of the object of intellectual disability and the practices of special education, as elaborated in my methodology presented in chapter 5. In this theoretical chapter I present below the understanding of discourse that underpins the method.

The Nature of Discourse

There are many different ways of understanding discourse and it is therefore useful to position my approach within this study. Macleod (2002) delineates three features of discourse around which contestation occurs. These are a) the underlying regularity of discourse, b) the constructive effects of discourse, and c) implications in terms of meanings and practices. I shall discuss each of these below.

The Underlying Regularity of Discourse

The regularity of discourse refers to the way in which “statements in a discourse cluster around culturally available understandings as to what constitutes a topic” (Macleod, 2002, p. 18). In its most general terms, discourse can be understood as an accepted way of talking about, understanding and delineating a specific phenomenon. However, the extent to which it can be viewed as coherent and stable remains an issue of contestation. A conception of discourse as highly regularised poses the danger of constructing discourse as an autonomous entity that is prior to the individual subject and wholly constructive of ways of acting and thinking (Curt, 1994). Macleod (2002) notes that the variability of discourse, within a system of dispersion over time and context, reflects the contested nature of discourses and their instability. However, regularity is to be found in that discourse consists not only of text but also of the rules and procedures for constructing text and a whole system of exclusions and inclusions (both material and textual) that limit what it is possible to say or do at any particular time relating to specific objects (Hook, 2001). As such there is a finitude to discourse that disallows certain formulations and permits others.

According to Foucault (1969/1972), the delineation of a specific discourse requires the dispersion of the initial *apparent* unities within a topic area or within a specific discipline. For example, intelligence testing should not be considered as a discourse bounded by the limits of the discipline of psychology itself but rather in the effects of discourse on relations of power and resistance between those who test and those who are tested.

The Constructive Effects of Discourse

A distinction can be made between strands of discourse work that focus on a) subjects as *discourse users* or b) as *constituted in discourse* (Bacchi, 2005). In the former, discourse can be seen as a tool that can be used by individuals to "*do* things in conversations (*micro*-contexts) for example, criticize, blame or present themselves in particular ways" (Wilbraham, 2004, p. 494). In this instance, it is the individual subject who has constructive effects through the use of discourse as a tool.

The second strand is more theory driven and looks to social processes in a macro-context with regard to ideology, power and subjectivity (Wilbraham, 2004). Foucault, with his concern with the operation of power in the construction of the subject is more closely aligned with the latter in seeing discourse as "practices that systematically form the objects of which they speak" (Foucault, 1969/1972, p. 49). Hacking (1999) elaborates on this process as it impacts on intellectual disability. He states that classification systems are not merely verbal descriptions but they have consequences reflected in the institutions, practices and interactions associated with those so classified. He goes on to describe how interactive kinds of classification are those where the object that is classified responds and reacts to the classification and adapts their behaviour in response. People within a classification can adopt or adapt ways of living so as to fit in with or defy classifications. Whatever the response, there is no way out of the classification system. This has consequences for the group, the *kind* of people, that is invoked in what Hacking (1999) terms: “the looping effect of human kinds” (p. 34).

Implications in Terms of Meanings and Practices

There is a range of views on the relationship of discourse to both text and to the extra-discursive (Macleod, 2002). These views engage with the questions: Is discourse confined to language or the text? Can it be distinguished from the context in which it occurs? If discourse is separate from the context, then, which is prior to the other – does discourse construct the material possibilities or is it the other way round? To what extent does discourse construct the subjects of which it speaks? All of these questions speak to drawing a line between discourse and the material world.

In this study, I adopt the view of discourse as being much broader than language alone, and including all objects that carry social meaning or can be given “interpretive gloss” (Parker, 1990, p. 193). However, this does not take away from the physical status of the objects that are included in this network of meaning. What it implies is that there is no way of knowing an object in the world without recourse to meaning or discourse – the perception of an object is always-already imbued with social meaning (Curt, 1994). Thus I do not make or contest truth claims about the neurological, organically based reality of intellectual disability as existing outside of discourse. Rather, I view claims made about intellectual disability as discursive events.

Within the discursive event, it is not language/text alone that deserves our attention. These events are located within the wider network of material power relations with multiple causes and effects. Thus it is not a matter of distinguishing between what we say about intellectual disability and what the truth/reality of intellectual disability really is. The concern lies in understanding how biological differences, language, technologies and social practices come together in specific discursive formations. This results in asking different questions about intellectual disability than those relating to its reality as a biological entity:

> How is it [intellectual disability] defined, and by whom? What kinds of individuals does it pick out? Does it refer to some "natural kind"? Is it simply a category created for specific political purposes, grouping together individuals who are deviant and undesirable? How is it that mental retardation became a unified category in the first

> place? What practices contributed to the constitution of the classification and classified subjects? (Carlson, 1998, p. 2)

The nature of these questions raises questions of agency and the ability of the individual to resist classification that I discuss further below.

Possibilities for Resistance

It is not the place within the current discussion to offer a detailed critique of Foucault's understanding of power and resistance as this is not a major focus of this study. However, I wish to highlight two points of contestation between post-structuralist theory and a materialist based social model of disability, notably a) the problem of agency (Hughes, 2005), and b) disability activism and human rights (Oliver, 1996). I shall discuss each of these below.

The Problem of Agency

With regard to agency, Hughes (2005) argues that the conception of disciplinary power as continuous and productive of individuals through processes of supervision and surveillance makes of the disabled subject an empty shell, an object in the circulation of power and knowledge. S/he is over-determined by the diffuse operation of power that makes certain ways of acting and thinking possible and excluding others. Such a view of the subject can be viewed as arising from Foucault's project of "de-individualizing, de-agenting, de-structuring" (Hook, 2007, p. 92). The rational, autonomous, unitary self is factored out of processes of resistance and in its place is situated the subject, as a product of power and knowledge.

The role of the autonomous self in resistance to disabling practices has, in itself been questioned. Erevelles (2002) notes that the uncritical positioning of resistance within the humanist mould of agency, autonomy and individual rights relegates the intellectually disabled person back to the margins from whence they came. By laying claim to a humanist subjectivity, the very reasons for exclusion (limited autonomy and agency by virtue of mental defect) are reinforced. The consequence of this for Epp (1999) is that a division within advocacy groups is created between those that are more capable of assuming rationality than others and excluding those who are deemed to be most defective.

The possibilities for resistance for intellectually disabled people appear to be greater where a diversity of views and discourses, which tell different stories, can be exposed. The notion of subjugated voices that represent the product of meticulous archaeological work and the careful attention to the voices of those who are disqualified from speaking represents an opportunity for resistance by the mere fact of bringing into knowledge that which was hidden by dominant discourses (Foucault, 1984). This is particularly useful in contexts where assumptions about the pre-discursive reality of the object of intellectual disability are so common as to make it a matter of little interest for social investigation (Quibell, 2005).

What is important to acknowledge here is that researchers into the field of intellectual disability accept that an understanding of the nature of agency for intellectually disabled people is not at all clear and is complicated by different styles of communication (Erevelles, 2005), restricted access to literacy (Kliewer, Biklen, & Kasa-Hendrickson, 2006), and assumptions about the naturalisation of impairment (Carlson, 2001).

Disability Activism and Human Rights

Intellectually disabled people are recognised as a specifically vulnerable group not least because of their ascribed inability to speak on their own behalf. A human rights approach is therefore invoked in consideration of their best interests. However, the notion of human rights bears some scrutiny. The aspects that will be considered are a) the universality of rights, b) the conceptualisation of the subject, and c) the power effects of rights.

An argument for the universality of human rights appeals to a common understanding of what it is to be human and what a person is entitled to by the very fact of their humanity with no other qualification than this (Sen, 2004). This humanity is portrayed as a timeless entity that is based upon appeals to reason and absolute truth. As such it minimises diversity and draws on what are deemed to be common or universal values. However, this position is undermined by a cultural critique, such as the position taken by representatives of Saudi Arabia at the United Nations, who contested the basic tenets of human rights, as articulated in the Universal Declaration of Human Rights, from an Islamic perspective (Otto, 1999). A Marxist critique, on the other hand, questions why political and civil rights are deemed as universal whereas economic and social rights are excluded from this domain and considered to be second order rights. Neither of these critiques questions the nature of absolute truth and argues instead for the superiority of their own version of the truth (Otto, 1999). A post-structuralist view of human rights begins, then, with a decentring of the universal subject.

The conceptualisation of the subject from a humanist perspective is based on an understanding of the individual as possessing an essence that precedes entry into human relations. This essence is that of a pre-constituted, rational individual entering autonomously into power relations. In contrast, post-structuralists view the subject as discursively constructed within relations of power and knowledge as I have discussed above. Otto (1999) argues that the humanist subject of universal claims is not an essence of humanity but rather is "always-already masculine, European, heterosexual middle class" (p. 23) and, I might add, physically and intellectually able. This subject then becomes the centre of rights, the norm relative to which excluded groups must stake their claim. The assumption of incompetence of the intellectually disabled allows them only weak claims relative to this norm. In the absence of rationality, a humanist view places the onus on those who know the best interests of the intellectually disabled to fight for their rights. However, this removes an essential component of human rights as reflecting choice and agency:

> a 'right', by definition, is concerned with agency, with the ability of an individual to make judgements and engage unimpeded in activities intimately associated with personal volition and an understanding of the possibilities. (Young & Quibell, 2000)

The question of whether the intellectually disabled person is served by a human rights agenda remains an open one, which will be further discussed in chapter 8.

The juridical nature of human rights can also obscure the operation of power. Otto (1999) notes that legal power is becoming increasingly disciplinary. Thus the granting of human rights can be accompanied by a plethora of disciplinary practices that institute a greater surveillance and pressure toward conformity. The complementary operation of legal and disciplinary power minimises the possibility of using the one to limit the other (Otto, 1999).

Finally it should be recognised that rights can serve to bolster the legitimacy claims of those who have won certain struggles. As such they are used to *consolidate* power relations rather than the more traditional view of human rights as a *challenge* to existing power structures. Stammers (1999) argues that once human rights become institutionalised in the form of law and policy, they serve to sustain power. It is for this reason that he argues for a critical view of human rights that balances the usefulness of an appeal to human rights against a careful scrutiny of what is being achieved through such an appeal. In this view it is not the case that human rights are inimical to social struggles but rather that everything is dangerous. This is particularly the case when those whose rights are being fought for are deemed unable to advocate for themselves, as is the case with intellectually disabled people (see chapter 8).

In concluding the discussion of a theoretical framework for this study I find it useful to draw on the feminist tendency within disability studies in order to make use of the insights that are offered from those considered to be marginalised or deviant from the white, male heterosexual, able-bodied norm.

Representation and simultaneity of subjectivities

The usefulness of feminist theorising for disability studies has been noted in the discussion on the disability/impairment binary. While there is a growing literature on feminist disability studies (cf. Garland-Thomson, 2005; Gerschick, 2000; Morris, 1993; Rohrer, 2005; Shildrick & Price, 1996) it is not within the scope of the current thesis to provide a full discussion of these developments. I shall focus on two specific aspects that are pertinent to the aims of this study, representation and the simultaneity of subjectivities. In chapter 8, I shall draw on feminist theorising of the ethics of care I order to understand better the data generated by this study.

Representation

Disabled people are subject to stereotyping that casts them as defective, dependent and vulnerable (Garland-Thomson, 2002). The popular understanding of intellectual disability is so stigmatised that numerous attempts have been made to change the label in order to alter the negative representation that goes with it (Loebenstein, 2005). The struggle against negative representations of intellectually disabled people as reflected in derogatory labels has been a focus of the self-advocacy movement in the UK and USA. Chappell et al. (2001), observing this trend, offer the following explanation:

> It also indicates a frustration regarding the terminology which non-disabled people use to describe people with learning difficulties; the lack of respect afforded to those who are defined by labels that others impose; and the difficulties in attempting to self-define when one exercises little control over one’s environment. (p. 47)

The issues of representation of intellectually disabled people are therefore central and will be discussed further in chapters 3, 6 and 8.

Subjectivity

The identity of devalued subject categories, such as women or disabled people, has been plagued by a tendency toward forced homogeneity within the category. While biologically deterministic accounts of disability and sex within a biomedical model tended to stereotype women and disabled people, the binary configurations of disability/impairment and sex/gender had the effect of emphasising disabled/female identity at the expense of others. This early view has been challenged by a recognition of the differences between women in terms of race, class, sexual practice and disability to name but a few (Garland-Thomson, 2002).

Similarly, the category of disability can be understood as a porous social category that is fluid and heterogeneous (Rohrer, 2005). At the one level, this accounts for the different types of impairment that occur and the differences that relate to severity of the disability, age of onset as well as socio-economic conditions, gender, and sexual orientation that are not disability related categories. In terms of intellectual disability, there are indications that a shift toward what Rohrer (2005) terms "simultaneity of subjectivities" has not yet occurred for intellectually disabled people, whose every action is ascribed to the intellectual impairment. As Rapley (2004) puts it, "in practice the hypothetical construct 'intellectual disability' continues to be reified as a core, or essential, aspect of personhood… an unambiguous identity that individuals *have,* whether they confess it or not" (p. 196). The struggle for the recognition of subjectivity that is not wholly biologically determined by notions of organic impairment is one that is far from over for intellectually disabled people (see chapters 5, 8 and 9).

Conclusion

In this chapter, I have outlined a theoretical framework for examining the construction of the intellectually disabled person in educational practices. My theoretical framework is one of post-structuralist disability studies where the binary of disability/impairment is broken down in such a way that both are viewed as discursively constructed. I examined a post-structuralist understanding of power with regard to intellectual disability, noting that the operation of disciplinary power in assessment and diagnosis links to norms of intellectual ability at the level of the population, in an exercise of bio-power. The government of disability is underpinned by the authority of the medical gaze that makes the truth of intellectual disability visible and establishes a positive knowledge about its nature. The subjectifying effects of pastoral power for the intellectually disabled subject were noted with a distinction made between subjectification as an external process, and subjectivisation as an internal one of working on the self. The role of discourse in the exercise of power is recognised as central and I argued that discourse should not be understood as merely relating to language, as distinct from the material world. Rather it should be seen as reflecting discursive formations where language, social practices and material elements are arranged in such a way as to make possible or constrain what it is possible to say and do in these contexts.

The post-structuralist conception of subjectivity is often viewed as problematic for understanding agency and resistance. I unpacked the notion of agency, centred on the notion of the rational, unitary self, raising some issues with regard to intellectual disability. This provided a background to a critical examination of a human rights perspective, which is frequently adopted within disability activism. Finally, I noted areas of interest from feminist disability studies that will prove to be particularly germane to an understanding of the discourses that are presented in chapters 6 and 7.

The framework presented here provides a background for my examination of the object of intellectual disability as a contingent social construct in chapter 3 and an analysis of educational practice in chapter 4. It is consistent with the methodology that I use in identifying discourses of intellectual disability and concomitant educational practice (chapter 5), frames the presentation of results (chapters 6 and 7) and is extended in the interpretation of results (chapter 8).

CHAPTER 3: THE SOCIAL CONSTRUCTION OF INTELLECTUAL DISABILITY

> In the past we used to be called labels like mentally handicapped, mentally retarded, intellectually handicapped, or mentally subnormal. We didn't like these labels as they kept us down. We choose to use 'learning difficulties' ourselves. It is a label which doesn't hurt us as much as those above. Jars should be labelled not people! (Central England People First Limited, 1996-2000)

> It could be argued that whilst the disability movement has fought the colonisers of disability (e.g. the medical and allied professions) for the right to define disability on their own terms, the fight against the colonisers of learning difficulty is of a different order; it is a fight against the denial of humanity itself; hence, this group insistence on being perceived as *people first*. (Gillman, Swain, & Heyman, 1997, p. 690)

In chapter 2, I elaborated my theoretical framework that draws on a post-structuralist, critical disability studies understanding of disability. Crucial to this framework is the undoing of the disability/impairment binary where the former is social and the latter organic/biological. While biomedical discourses of intellectual disability view it as an individual property, based in organic deficit, the above quotes highlight the contested nature of the category of intellectual disability as a “human kind” (Hacking, 1999). At the same time these quotes emphasise both the power to make, and the resistance to break, this particular classification.

In this chapter, I contend that intellectual disability has largely been located within a medical or special educational frame as a problem to be studied, solved and treated, grounded within a positivist scientific approach. In much of the current literature intellectual disability is portrayed as “an historically continuous, clinico-medical, thing-in-the-world that can be ‘diagnosed’” (Rapley, 2004, p.31). In South Africa there is an understanding, explicit or implicit, that intellectual disability exists out there waiting to be identified and treated:

> Establishing *the real prevalence* [italics added] of intellectual disability is difficult because factors such as the identification system used, the level of technological development of the community and the socio-economic level of the particular group should all be taken into account. (Jooste & Jooste, 2005, p. 381)

Within such an approach, social factors are considered as extraneous variables that obscure the hidden truth of intellectual disability. The recognition that the disability itself might be socially constructed does not find a place in this frame, despite a growing recognition of this in the literature (cf. Goodley, 2001; Hacking, 1999; McClimens, 2002; Rapley, 2004).

This review will examine the conditions of possibility that created the problem of intellectual disability and the ways in which the dominant understanding of intellectual disability, "was hardened into an unalterable form in the long baking process of history" (Foucault, 1984, p. 79). I shall therefore focus on what I have designated as key moments in the construction of the problem of intellectual disability. While many of these events have their roots in Western Europe or the United States, I shall trace their transfer to the South African context, as the similarities and differences in their implementation are instructive. In the subsequent chapter, I shall elaborate on how these representations are deployed within the educational field. These two literature review chapters are fundamental to the methodology, Q-methodology that I shall describe in detail in chapter 5.

Key Moments in the Construction of Intellectual Disability

In undertaking this discussion, it is noted that the use of certain terminology from different historical periods is considered to be insulting to people who are currently classified as intellectually disabled. The rejection of these labels forms a major thrust of the self-advocacy movement, as is noted in the opening quote of this chapter. While I respect this plea in the current context, I maintain the use of offensive terms in a discussion of the historical development of the notion of intellectual disability. This is because I reject the view that intellectual disability is the same objective entity existing in the world out there over time and it is merely the labels that have changed. What we understand as intellectual disability today cannot be seen as identical with idiocy, mental retardation, imbecility and other similarly offensive terms. The terms are used in keeping with their times in my discussion, not because terminology is not important but rather because it is crucially important. The use of the term idiot or imbecile in a certain period indicates certain ways of thinking and acting that I highlight as leaving their traces in the present.

My focus in this chapter is on the construction of intellectual disability though broad social practices which constitute the (in)educable subject that presents as a problem for the education system. In order to do this I have identified several key points in the way in which intellectual disability is configured. These are a) confinement and the asylum, b) the philanthropic institution, c) the problem of degeneracy and eugenics, d) the development of the institution in South Africa, e) normalisation, and f) normalisation in South Africa.

This is by no means a comprehensive discussion but is rather a focus on those events that I have noted from the literature that are instructive with regard to the educational practices that are discussed in chapter 4. My purpose is not to review long forgotten events in the past but rather to explore accounts of intellectual disability within social and historical context in order to tease out the complex configurations of social and biological understandings that have come to be grouped together under the contemporary classification of intellectual disability.

Confinement and the Asylum

Whereas idiocy was recognised as a condition long before the nineteenth century, the institutionalisation of those so labelled only appeared much later. In this section I shall examine what made this response possible and its constitutive effects for the problem of intellectual disability.

In his work *Madness and Civilisation,* Foucault (1967/ 2006) traces the history of the increasing differentiation and segregation of those who were identified as unfit for the changing social order. In a process that he terms the Great Confinement, up to 1% of the French population was confined into poor houses in the late seventeenth century. At this point there was no medical connotation to the confinement and these poor houses could in no way be associated with the function of a hospital. The confinement of this group was largely a response to failed exclusionary measures to keep the poor out of the cities, replacing these measures with confinement. The contract entered into between the state and the individual was one in which the state would provide for the physical requirements of the pauper who would offer in exchange their liberty, accepting “the physical and moral constraint of confinement” (Foucault, 1967/2006, p. 45). It is this contract that informs the institutionalisation of those who were later differentiated from a relatively undefined mass, through a progressively finer division of people into different kinds, such as idiots, mental defectives and feeble-minded.

In the course of the eighteenth century, the understanding of poverty moved away from being a moral issue of indigence toward recognition of the economic value of the pauper if his or her labour was put to good use. The purposes of confinement changed. Those who were confined for moral flaws such as family transgressions, indigence, sloth and similar failings, were released from confinement to provide labour and those that remained were the insane and the criminal: "Confinement is thus definitively reserved for certain categories of convicted criminals and for madmen" (Foucault, 1967/2006, p. 224). Further differentiation then takes place between the insane and the criminal through the drive to place the mad in hospitals and created the "New Division" (p. 210) where the divide was claimed to "free the mad from a lamentable confusion with the felonious, to separate the innocence of unreason from the guilt of crime" (pp. 210-211). Thus the construction of the asylum became necessary. Within the asylum, idiocy was an identified condition but did not have specific practices attached to it.

According to Rose (1985), the undifferentiated nature of the asylum came under the medical gaze as the hospital gained ground as the site of treatment for physical illness. As patients were treated in the institution of the hospital, it became possible to compare and contrast their symptoms, diagnoses and prognoses across large numbers of people. The individual became an object of study and healing through consideration of their deviancy or conformity to these norms. Pinel, one of the earliest physicians concerned with mental illness, introduced these methods into the asylum. While this might be seen as the application of medical knowledge in the asylum, Foucault cautions that medical knowledge had little to contribute. Rather it was the moral authority of the doctor, symbolising the values of bourgeois society that was invoked through the medical presence in the asylum. The medical control of the asylum moved away "from a transparent and clear moral practice, gradually forgotten as positivism imposed its myths of scientific objectivity; a practice forgotten in its origins and its meaning, but always used and always present." (Foucault, 1967/2006 , p. 262).

To the extent that the asylum relied on coercion and chains, it was ineffective in the treatment of madness. The mythic intervention of Pinel in casting off the chains of the insane reflects a certainty of authority rather than a lessening of control (Rose, 1985). Such an approach depended on a moral treatment of the insane that presupposed that at the core of madness there remained a moral sensibility that could be drawn upon to affect a cure. This sensibility could be awakened through work and the application of religious principles.

According to Rose (1985), Pinel proposed four categories of mental illness: dementia, melancholia, mania and idiocy. Idiocy was set apart as having a relatively less complex set of symptoms (marked by absence of intellectual faculties) with an organic basis, and as being incurable. While the category posed interesting legal problems, it remained marginal to mental medicine, which centred on a therapeutic practice that appealed to a core of reason or humanity that remained in the insane, but was considered to be absent in the idiot. This conviction made idiots impervious to treatment according to Esquirol and Pinel (Rose, 1985).

The Philanthropic Institution

It was the method of moral treatment that was applied to Victor, the Wild Boy of Aveyron, a feral child found in France at the beginning of the nineteenth century, that initiated a change in understanding of the treatment of idiocy (Rose, 1985). Victor's education was undertaken by Itard who was at pains to distinguish between the case of a child who had been deprived of all normal socialisation and the case of the idiot:

> Itard, not believing idiocy curable, … undertook this education. In devoting himself to this case, his object was not to improve or cure an idiot; it was "to solve the metaphysical problem of determining what might be the degree of intelligence and the nature of the ideas in a lad, who, deprived from birth of all education, should have lived entirely separated from the individuals of his kind"[no reference supplied for quote, presumably Itard]. (Seguin, 1907, ¶ 40)

The work of Itard with Victor was based on awakening the child's moral sensibilities, an approach that Seguin endorses as being appropriate for a child who has been deprived of social contact. The practice of moral treatment was, at this stage, aligned with social, rather than organic, causes of incompetence. However Seguin (1907) notes:

> For more than a year Itard followed this psychological programme, perfectly well adapted to the education of a savage. But he seems, after this time, to have suspected that there were other impediments besides savageness in his pupil; for, though he never formally acknowledged it, he framed, in about 1802, an entirely new programme, more fitted for an idiot than for a savage, whose foundation was physiology… (¶ 46).

The members of the French Academy attributed the progress that Itard was able to make with Victor to the brilliance of his moral and physiological methods and the limit of progress was ascribed to the biological limitations of the child, who, it was finally agreed within the Academy, was in fact an idiot:

> This class of the Academy acknowledges that it was impossible for the institutor to put in his lessons, exercises, and experiments more intelligence, sagacity, patience, courage; and that if he has not obtained a greater success, it must be attributed, not to any lack of zeal or talent but to the imperfection of the organs of the subject upon which he worked. (Dacier quoted in Seguin 1907, ¶ 64)

If the boy had been a savage, he would have provided Itard with an opportunity to demonstrate the importance and effectiveness of his philosophical method in educating even the most difficult cases, but idiocy was beyond this scope.

Seguin, on the other hand, took the opinion of the Academy in a positive light, as a sign that the idiot could, in his view, be educated. Once the physiology was awakened, the higher functions could then begin to be taught as Seguin (1907) describes:

> The general training embraces the muscular, imitative, nervous, and reflective functions, susceptible of being called into play at any moment. All that pertains to movement, as locomotion and special motions; prehension, manipulation, and palpation, by dint of strength, or exquisite delicacy; imitation and communication from mind to mind, through languages, signs, and symbols; all that is to be treated thoroughly. Then, from imitation is derived drawing; from drawing, writing; from writing, reading; which implies the most extended use of the voice in speaking, music, etc.(¶ 76)

Families could not undertake this task as they did not have these special skills. This laid the groundwork for the establishment of institutions specifically directed toward the education of the mentally defective. Philanthropists and medical doctors worked together to establish institutions both in Europe and in the United States where the idiot could be housed and educated (cf. Armstrong, 2002; Goodheart, 2004; Seguin, 1907).

Seguin (1907) quotes extensively from a speech by the Rev. Samuel J. May on the occasion of the opening of the first school for idiots in the USA in Syracuse in 1854. The Rev. May ponders on what the purpose of evil is in a world where God is in control and he agonises over the challenges posed by idiocy:

> But there was idiocy —idiocy so appalling in its appearance, so hopeless in its nature; what could be the use of such an evil? It were not enough to point to it as a consequence of the violation of some of the essential laws of generation. If that were all, its end would be punishment. I ventured, therefore, to declare with an emphasis enhanced, somewhat, perhaps, by a lurking distrust of the prediction, that the time would come when access would be found to the idiotic brain.

> Two or three years afterwards I read a brief announcement that in Paris they had succeeded in educating idiots. I flew to her who would be most likely to sympathize in my joy, shouting, ‘Wife, my prophecy is fulfilled! Idiots have been educated!’ (May quoted in Seguin, 1907, ¶ 8,9)

Indeed it is the physiological method, as the correct means of training, that “provides access to the idiotic brain”. The philanthropic argument is then based on the rejection that idiocy can be sent by God as a punishment and concludes that the hidden purposes of this affliction are to challenge human ingenuity and to provide an opportunity for charity. Thus Seguin (1907) expresses great optimism on the roles that the institution could play in the development of physiological methods for the treatment of idiocy, while at the same time enhancing anthropological knowledge of humanity. As such these institutions were “monuments of philanthropy” (Seguin, 1907, ¶20) which served the dual purpose of doing good to individuals and furthering the study of the mind. According to Trent (1994), Seguin saw the aim of education for the idiot as being to “attain a respectable mediocrity” (p. 53) that would allow him or her to function in the community. Purely custodial care should be reserved for the lower functioning imbecile. However, the distinction between the custodial and educational functions of the institution was to change with increasing industrialisation and a social concern with the limited usefulness of idiots.

Goodheart (2004) traces the changes in the purpose of the institution in a case study of one of the first schools for imbeciles in the United States. These early institutions were established mainly for the wealthy, who could afford to place their children there, and the problem of idiocy tied to poverty and idleness loomed large with the growing concern with the overall fitness and productivity of populations. This was to find its expression in the combined medical and social project of eugenics.

The Problem of Degeneracy and Eugenics

Eugenic thinking was made possible through certain shifts in thinking that occurred with the industrialisation of Europe in the mid- eighteenth century, where individuals came to be conceived of as members of populations. Foucault (1978) describes this development:

> Governments perceived that they were not dealing simply with subjects, or even with a “people” but with a “population”, with its specific phenomena and its peculiar

> variables: birth and death rates, life expectancy, fertility, state of health, frequency of illnesses, patterns of diet and habitation. (p. 25)

The construction of a well-ordered political machine with enlightened administration depended on knowledge of the population through statistics, the science of the state (Rose, 1985). As noted in chapter 2, intellectual disability became not only a concern of individual bodies, requiring diagnosis and treatment, but it was also constructed as a problem of the biological species in the exercise of bio-power in the newly emergent rationale of governmentality.

By the end of the nineteenth century, social and medical science came together to formulate the concerns of degeneracy. The understanding that mental pathology (as manifest in anti-social behaviour) was organic and inheritable, with the possibility of acquired characteristics being passed from one generation to the next, was developed through medical science. The social concerns with the control of populations made this a matter of public importance to be addressed through public policy. Moral judgements of vice, corruption and threat were provided with a medico-psychological rationale. This was complemented by the view that deviations from the norm were accentuated from one generation to the next, thereby leading to further degeneracy and ultimate extinction of the race. Through the application of a social Darwinism, it was not merely the degeneration of a lineage that was a concern but rather the degeneration of the species as a whole. It became a matter of public concern and regulation to ensure that the bloodline was improved through facilitating the breeding of those who were deemed socially useful and preventing further generations of moral degenerates being born (Rose, 1985).

In terms of intellectual disability, there was a transfer of judgement of fitness of the individual from the ethical/religious domain to the domain of medical science. While idiots would now require care as unproductive members of society, this care was as much a protection of society from their degenerate genes and immoral behaviour as it was for their own protection. The institutional practices and overcrowding of the early institutions bolstered the belief that the condition was incurable and could not be mitigated:

> The high expectations for education of his father’s [Dr. Henry Knight – founder of the Connecticut School for Imbeciles] generation were not warranted. The best the asylum could do was to contain the mentally retarded, prevent their procreation, and train some to self-sufficiency within the institution. (Goodheart, 2004, p. 107)

Whereas the first generation of philanthropic institutions was motivated by religious benevolence and the desire to instil middle class, Protestant norms amongst this unfortunate group, the second generation was more motivated through fear of difference and its impact on the genetic stock of the population and strongly influenced by the new science of eugenics developed in the early twentieth century (Goodheart, 2004).

The urgency of the need to contain the mental defective is reflected in the following statement by Fernald before the American Association for the Study of the Feeble-Minded in June 1912. He begins by stating the biological fact of idiocy:

> The fact that feeble-mindedness is the result of pathological conditions of the brain, either gross lesions caused by faulty development or by the destructive results of disease, or perhaps numerical deficiency or imperfect evolution of the ultimate cortical cells, makes it obvious that the resulting mental defect is incurable and permanent. (¶ 5)

Fernald (1912) then expounds upon the social consequences of this pathological condition, noting the dire effects on the population if this menace is allowed to go unchecked:

> The social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. The great majority ultimately become public charges in some form. They cause unutterable sorrow at home and are a menace and danger to the community. Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves. The feeble-minded woman who marries is twice as prolific as the normal woman. (¶ 14)

In this perspective the feeble-minded person is entirely lacking in agency or responsibility. The social ills that befall them are due to their biological deficit, which is incurable. They are portrayed as impervious to socialisation and their elimination, if not of the current generation, then at least of future generations, is seen as a viable course of action. The feeble-minded person is entirely constructed by their possible impact on those who are not so labeled, such that the ‘unutterable sorrow’ that they cause is of greater concern than their lives. Dr. Thomsen Von Colditz expresses this view below, in an expert comment on the acquittal of Dr. Haiselden for withholding treatment from the disabled Bollinger baby in the United States in1915:

> The baby has not the beauty of a plant. It would be a sorrow for the parents to look upon so long as the child lived and a burden. I think such a person that lives like a plant or an animal in the human family should not be allowed to give unhappiness by

> living. (Dr. Haiselden And The Bollinger Baby - Does Humanity Demand The Saving Of Defective Babies?, 1915)

While these extreme views would not find favour in current times, Erevelles (2002) notes that in the case of severe cognitive disability, “these death invoking discourses constitute disability as marking the outermost limits of human existence” (p.6).

Representation of idiocy within a eugenic understanding proceeded on gendered lines. The feeble-minded woman was identified variously as immoral, a carrier of venereal disease, a bearer of defective children, prolific (Fernald, 1912), sexually vulnerable (Goodheart, 2004), a dangerous symbol of degenerative procreation, in need of protection, a danger to society (Carlson, 2001) and many other restrictive and constitutive labels. McDonagh (2000) describes the representation of feeble-mindedness in nineteenth century Britain through examinations of literary representations of that period. The feeble-minded woman is almost totally identified with a threatening sexuality and excessive bodily appetites that are either absent or controlled in the normal woman. At the same time, she is represented as a sexual innocent, requiring masculine protection. The male idiot is largely represented as being incapable of managing money. He is represented as a debased form of masculinity that is sexually diminished, incapable as he is of passing on his assets and his name. By the end of the nineteenth century, these representations serve to validate a eugenic conception of degeneracy – the feeble-minded man must be prevented from becoming a criminal and the feeble-minded woman must be prevented from corrupting more valued lives with her indiscriminate sexuality. Both must be prevented from breeding.

A complex picture of the social evil of the mental defective emerges, interweaving innocence and immorality. The concern is less for the impact that their immoral behaviour will have on the mental defective him or herself but rather the disruption that they are capable of causing in more valued lives. The problem of feeble-mindedness is no longer one that is located in individual bodies but is a degenerate property of society as a whole, insofar as idiocy is biological, heritable and cumulative over generations. The institution serves the role of protecting the current generation of mental defectives and preventing them from causing disruption. It protects future generations and society as a whole through the control of fertility of defective individuals. In this sense the detailed description of the individual has a totalising effect that links with the mechanisms of bio-power in the government of the subject.

A significant aspect of institutionalisation is the necessity of separating the child from the family. Since the heredity nature of mental defect places the cause of the defect within the family, there can be no chance for improvement without removal from the cause. The cause was not only seen as genetic but, given the overall degeneracy of such families with defective genes, it was also evident in their childrearing. Professional descriptions identify families as being incapable of caring for their child as a confirmation of the heredity nature of degeneracy:

> In addition to documenting egregious abuses of the retarded in Connecticut, the survey also identified parental ‘bad habits’ — a moral Lamarckianism — as a major cause of retardation… In addition to consanguinity, intemperance, licentiousness and filthiness were implicated. (Goodheart, 2004, p. 96)

On the other hand, there are descriptions of how parents needed to be persuaded and informed of the need for institutionalisation, where this was the correct treatment identified by the professionals:

> At the proper time the parents should be informed of the condition of the child, of the necessity for life long supervision and of the probable need of institution treatment. Sooner or later the parents will probably be willing to allow their child to be cared for in the institution. The parents who are not willing should be allowed the custody of their child, with the understanding that he [sic] shall be properly cared and provided for during his life, that he shall not be allowed to get into mischief and that he shall be prevented from parenthood. Whenever the parents or friends are unwilling or incapable of performing these duties, the law should provide that the child shall be forcibly placed in an institution, or otherwise legally supervised. (Fernald, 1912, ¶ 28)

The medical profession and the law intervene in the family relation between parent and the feeble-minded child. Their role with respect to their mentally defective child is a different one to that prescribed for the ‘normal’ child. The child becomes the concern of the state rather than that of the family and the views of parents and families themselves are hidden from view, drowned out by professional voices (Read, 2004).

Development of the Institution in South Africa

The early approach to the problem of intellectual disability in South Africa is similar to that described in Europe and in America. Indigenous societies in South Africa had no equivalent to the asylum at the start of colonisation (Swartz, 2008). While there can be the temptation to romanticise this lack of segregation, where the mad are prophets and the village idiot an accepted feature of daily life, Swartz (2008) warns that there are also accounts of ostracism and extermination of the mentally disordered/defective.

According to Foster (1990), the object of idiocy did not emerge as a concern prior to 1800. The process of differentiation described in Europe is reflected in colonial South Africa, with Somerset Hospital in Cape Town serving as a catch-all institution for the insane, the physically ill, paupers and lepers (Swartz, 2008). Subsequent to this, there is only indirect mention through records in general hospitals of mental disorder/defect until 1846 when the first asylum was formally set up on Robben Island. At this point, there was no distinction made between mental handicap and mental illness, similar to the lack of differentiation evidenced in the early European poor houses. Foster (1990) records a litany of reports decrying the appalling conditions on the island stretching from 1848 to its final closure in 1920. The recommendations of these reports identify the inhumane conditions of the asylum as reasons for closure but clearly this was not sufficient grounds for effective action. It was here at Robben Island that the early racialisation of services was evident in a report from 1861 that noted the separation of “coloured” (a term used in the South African context to denote a person of mixed racial origin) from white men.

In the period 1876-1895 one lunatic asylum was established in each of the future provinces of South Africa. In terms of this process Foster (1990) identifies 5 important characteristics:
Institutionalisation in the form of the asylum was established as opposed to philanthropic institutions that offered some form of education.

1. The asylums, as in Europe and the United States, fell under the jurisdiction of the medical profession “due to the fact that the Cape inherited conceptions of dealing with the insane directly from the British. The majority of medical superintendents of South African asylums had been educated in Britain.” (Foster, 1990, p. 29).
2. Lunatics came to be seen as a certain class of patients with the need for their own segregated provision. Within this class, there was initially little recognition of mental deficiency or idiocy, which was largely classed as a form of lunacy. The lines of segregation within the class of lunatics focused on the distinction to be made between violent and non-violent patients, paying and non-paying patients, men and women and between racial categories. Only in the later part of the nineteenth century did a

rudimentary classification of types of insanity and a distinction between the feeble-minded and the insane begin to emerge.

3. The control of mental disorder was racialised from the 1860s when inmates on Robben Island were recorded by gender and race. All the asylums have records indicating that segregation by race and gender was more significant than by category of mental disorder. While separate asylums were not usually established, strict segregation was maintained within the asylum. White patients received better food, treatment and accommodation, while black patients experienced harsher conditions and were often expected to provide labour for the maintenance of the white inmates (Swartz, 2008).
4. Legislation concerning mental disorder proceeded at the same time as the process of institutionalisation. They could be seen as part of the same process.

The rise of the institution in the colonial setting of South Africa bears some similarities to the situation in Britain and America, occurring some 40 year later and with less comprehensiveness (Foster, 1990). The institutions would also seem to differ to the degree that the early European institutions had a partly philanthropic and scientific agenda in the early, elitist years. An exception to this would be schools such as the Institute for Imbecile Children, established in 1894 in Grahamstown, which was the first of its kind in Africa and reserved only for white children (Swartz, 2008).

By 1916, the mentally defective were defined as follows in the *Mental Disorders Act no 38 of 1916* as belonging in one of three categories:

1. An idiot was regarded as ‘so deeply defective in mind from birth, or from an early age, as to be unable to guard himself [sic] against common physical danger’.
2. An imbecile was regarded as capable of guarding against common dangers, but not capable of ‘managing himself or his affairs, or if a child of being taught to do so’.
3. A feeble-minded person was defined as incapable of competing on equal terms with his normal fellows or of managing himself and his affairs with ordinary prudence’. Such a person required ‘care, supervision and control for his own protection and that of others.’ (Foster, 1990, p. 39)

Whereas (white) idiots and imbeciles, according to this classification, were only catered for in institutions such as Alexandria and Witrand, (white) feeble-minded children were to be found in special classes within the regular schooling system (Malherbe, 1932). It is this group of feeble-minded children that assumed a huge importance in psychological and social research in the colonial setting, as they blurred the significant features of the racial divide. The dangers of feeble-mindedness were highlighted, as Western concerns with degeneracy (similar to Fernald in 1912 in the USA, cited above) filtered into the colony after about 1913 and were used to bolster racial divides. The dangers are enumerated by Dunston, Commissioner of Mental Hygiene from 1916-1932, who foresaw dire consequences if mental deficiency was not properly dealt with, since (white) mental defectives would become:

> more degraded and more useless and swell the ranks of the criminal, poor white, inebriate and prostitute classes thus leading to enormous unnecessary expenditure, not only by the state, on prisons, mental hospitals, charities but also by church, public and private charitable organizations. (Cited in Foster, 2008, p. 97)

The threat of having to include certain forms of behaviour that belonged to the racial “other” within one’s own race was overwhelming and the response was to uplift the poor white so as to restore the proper distance between the races. For these reasons considerable energy and resources were directed toward the problem of mental deficiency during the period of union of South Africa in 1910 to the beginning of the apartheid era in 1948. This will be discussed further in chapter 4.

The construction of intellectual disability in the early twentieth century reflected a specifically racial concern borne out of the colonial enterprise. The lines of division were set between levels of severity (imbecile, idiot and feeble-minded) within the white race group. The black group remained undifferentiated and was not identified as a problem until much later when educational provision was brought into consideration (see chapter 4 for further discussion). While the full range of the complexities of the intersection between race and disability in the colonial context are beyond the scope of the current discussion, it is notable that there is very little recognition in the literature of the ways in which apartheid and colonialism constructed disability differently for the colonising population and the native population. Foster (1990) suggests that the repressive controls placed on the movement and rights of the native population were considered sufficient to discipline this group. However, the dangerous elements of the white population (those who would blur the absolute racial boundaries through poverty, miscegenation and behaviour outside of the Western norms) required more subtle and productive forms of control. It is perhaps because of this disjuncture between the colonial and the colonised that the concept of normalisation, which I shall discuss below, never really took root in South Africa.

Normalisation

Normalisation with respect to intellectual disability must be distinguished from the way that the term is used in the Foucauldian sense —that is of regulation through the application of hierarchical judgement and measurement. Specifically applied to delivery of services for intellectually disabled people, normalisation is an approach that attempts to undo the work achieved by the normalising judgement, by making normal again that which has been regulated as abnormal. It has its roots in Denmark with the work of Nirje who advocated that the life of the retarded person should be as similar as possible to that of the normal person. This would involve normal rhythms to the day, normal respect and normal experiences of the life-cycle amongst others (Lea, 1990).

The principles of normalisation were further articulated by Wolfensberger (1969) and have been very influential in the planning and delivery of services for intellectually disabled people in Britain, Europe and the United States. Wolfensberger later adopted the term "social role valorisation" (SRV), emphasising the thrust to integrate devalued individuals into society in normal jobs and education so as to enable them to engage in socially valued activities and to develop a positive social role and image. Normalisation or SRV continues to be a position of orthodoxy in the provision of residential care and employment for intellectually disabled people in these countries (Yates, Dyson, & Hiles, 2008).

Normalisation has its basis in the understanding of stigma put forward by Goffman (1963) as "an attribute that is deeply discrediting" (p.3). He notes that the attribute itself is arbitrary and functions in different ways at different times, since stigma is a relationship between an attribute and a stereotype rather than an entity in itself (Goffman, 1963). The fact that this relationship is arbitrary implies that it can be manipulated and it is this potential that is exploited in the normalisation principle by ensuring that the stigmatised person associates with more socially valued people who are perceived as normal. As Chappell (1997) puts it:

> The normalisation principle argues that people with learning difficulties are devalued by society and have stigmatised identities. A vicious circle of devalued identities reinforced by poor quality services is created. Putting into practice the normalisation principle will transform the vicious circle into a virtuous circle of high quality services which will create high quality lifestyles and enable people with learning difficulties to mix with those who have socially valued identities. (Chappell, 1997, p.45)

This approach was closely associated with a move to de-institutionalise intellectually disabled people and was thus seen as a progressive movement at its inception. Such was the belief in its potential to liberate people with intellectual disability, and the hostility that this engendered amongst those who held more traditional views at the time, that it became very difficult to critique the principle. At the same time it offered an inspiring vision of what services could or should be like for intellectually disabled people (Chappell, 1997). Trent (1994) notes the zeal with which Wolfensberger and his acolytes implemented assessments of community life in terms of the extent to which they "succeeded in reaching Wolfensberger's vision of normalization, social integration, and dignity" (p. 263).

Simpson (1998) points out the links between normalisation and a redefinition of mental retardation in the 1960s. At this time, the American Association on Mental Deficiency proposed a definition of mental retardation that elevated 'impairment in adaptive behaviour' to the level of a diagnostic criterion as opposed to a secondary symptom. This gave rise to a new optimism about the education of intellectually disabled people in that changes in behaviour could not only ameliorate but also go some way to curing the condition itself. It also granted an extensive role to psychologists as agents of behavioural supervision.

Simpson (1998) further examines the relationship of normalisation to sociological theory as it is predicated upon the work of Goffman with regard to total institutions and stigma. The anti-institutional impetus of Goffman's work provided powerful arguments, which could be directed at the largely medical control of these organisations. However, the adoption of a largely behaviourist psychology with its positivist epistemology was at odds with the interactionism in sociology that adopted a more idealist bent. The connection between the sociological and psychological was therefore lost.

The behaviourist tendency in psychology resulted in a weakening of a human rights perspective within normalisation. In the case of the mentally retarded, the significance given to social competence meant that it became a professional responsibility to modify behaviour in such a way that it became more normal. The intellectually disabled person was seen as not being competent to behave appropriately and therefore, his or her behaviour became the therapeutic responsibility of the professional as part of the management of the intellectually disabled person. As the responsibility for competence passed to the professional, it created the possible conditions for "'detaching' behaviour from the transcendent human essence of the retarded individual" (Simpson, 1998, p. 6). The notion of agency, so essential to a human rights perspective, was therefore replaced with disciplinary powers of the psy-complex.

Normalisation/SRV has been criticised in that it establishes the devalued identity of the stigmatised person and reinforces existing social patterns of stigmatisation without challenging the very basis for discrimination and inequality. As Chappell (1997) notes, normalisation:

> demonstrates an unquestioning acceptance of the concept of stigmatised identities. There is no recognition of stigma itself as a social construct: a mark imposed by an economically, socially and politically powerful group on one which is economically, socially and politically disempowered. (Chappell, 1997, p. 49)

It is also an approach that developed in the context of service provision rather than in terms of identity formation and as such has the effect of casting its subjects into a perpetually dependent role of receiving services.

When the concept of counteracting stigma is used as a basis for service provision, the normative force (akin to the Foucauldian sense of normalisation) of normalisation is apparent. It focuses on developing normal behaviour without questioning what this behaviour is and whose interests it might serve. The insidious nature of this discourse is that it is couched in terms of the best interests of the intellectually disabled person while fundamentally denying this person their agency through the focus on social competence. However, it remains a powerful influence on policy development in Britain to this day and can be seen to be the determinant behind a whole range of community services (Simpson, 1998). These arrangements, many of them perceived to constitute positive changes, remain unexamined as to their power effects.

Yates, et al. (2008) call for a Foucauldian deconstruction of normalisation that focuses on the relationship between the social and the individual in the vein of critical disability studies noted in chapter 2. They identify a paradox within normalisation where the social is seen as prior to and constructive of intellectual disability and yet the presence of organic impairment is tacitly accepted. This preserves the notion of the individual (impairment)/social (disability) binary that I have noted in chapter 2 as a problematic distinction in understanding disabled subjectivity. This paradox precludes an exploration of how social processes operate in constructing subjectivity of one kind or another and obscures the operation of power in the principle of normalisation to *prescribe* rather than *describe* behaviour.

Normalisation in South Africa

Foster (1990) noted that the influence of normalisation or SRV was negligible at the time of writing in South Africa. A review of current South African literature would indicate that this remains the case today, 19 years later. Literature searches on disability and intellectual disability in South Africa reveal a focus on inclusive education, health issues and employment but there is no discussion of the concerns of the intellectually disabled adult with respect to services and social inclusion. This situation in South Africa is in sharp contrast to many Western countries where intellectually disabled adults are enmeshed in complex systems of community care and self-advocacy (cf. Braddock, Emerson, Felce, & Stancliffe, 2001; Central England People First Limited, 1996-2000; Quibell, 2005), many of which are based on principles of normalisation. However, normalisation deserves our attention in the discussion of intellectually disabled people in South Africa for two reasons. Firstly, it is instructive to consider why this approach has not been imported in the same way as the eugenic and philanthropic trends and secondly, because the conception of normalisation informs the educational practice of mainstreaming which has been contrasted with inclusion.

In terms of the relatively insignificant uptake of normalisation, Lea (1990) advocated for its use in apartheid South Africa, asserting its potential to affirm the value and worth of the intellectually disabled person as part of an overall human rights project that should inform South African policy making. However, she was pessimistic about its usefulness in South Africa at the time of her writing, since in line with all other policy regarding mental handicap, it would only be implemented for white people. She predicted that community integration within normalisation would be more widely adopted where there were well-developed services, and that institutions would continue to be motivated for where there are large numbers that require services. She also singled out the apartheid imperative to segregate on lines of difference, most notably race, as a negative force for normalisation. The massive changes that have taken place in South Africa since 1990 have invalidated these predictions but it would be unwise to disregard the conceptual underpinnings that are still evident to this day in terms of discourses around disability. This is especially clear in certain conceptions of education for disabled children, which brings us to the second issue that relates to normalisation, that of educational ‘mainstreaming’. This will be discussed further in chapter 4.

Underlying Tensions

What has become apparent in the above discussion is that there are complex interactions between organic/biological and social conceptions of intellectual disability. Thus an organic account of intellectual disability can be combined with one that sees the intellectually disabled person as incapable of development (such as Itard’s view) or with a more optimistic view that strives for improvability within the limitations imposed by organic defect (as espoused by Seguin). In the eugenic movement the organic defect of the individual is linked to the biological health of the species and becomes implicated in the exercise of bio-power for regulating subjects. Within normalisation approaches, the organic is ignored but has a tacit presence as a property of the individual that determines their perceived value in society. The complexity of these interactions is often glossed over in analyses that adopt simple binaries, such as the social model of disability as discussed in chapter 2. My aim is to provide a complex and nuanced account of social and biological discourses of intellectual disability through analysing underlying tensions between oppositions.

In order to do this, I have found it useful to draw on the type of oppositional analysis developed by Carlson (1998) in her Foucauldian analysis of the institutional world of mental retardation. Such an analysis undermines the impression that there is an historical, orderly process in our understanding of intellectual disability:

> There is a tendency to present the history of mental retardation as a series of decisive, temporal and conceptual shifts. I argue that, though these seem to be discontinuous moments in this history, they rely upon a series of underlying tensions which are internal to the classification itself. (Carlson, 1998, p. 10)

The importance of these dimensions is that they structure the debates that can take place and circumscribe what it is possible to say and do about intellectual disability. The oppositions that Carlson (1998) identifies are discussed below.

Qualitative and quantitative difference: The concern here is to what extent is the intellectually disabled person different from others in terms of degree or in kind. Accounts that draw on qualitative difference emphasise disjuncture between the ‘normal’ and the ‘retarded’, a difference in kind whereas a quantitative account would consider intellectual disability as a difference in degree of competence. Normalisation is based on a quantitative conception of difference whereas early notions of idiocy such as those held by Itard indicate a qualitative understanding of difference.

Organic vs. non-organic: The tension that exists within this dimension is between organic explanations of behaviour as opposed to accounts that include environmental considerations. A distinction can usefully be made here between organic (at the level of the individual) and biological (at the level of the species). All of the approaches described above are predicated on an organic understanding of intellectual disability to the extent that it is viewed as a defect in the individual. The eugenic understanding adopts a strongly biological perspective relative to other approaches.

Static and dynamic definitions: This dimension relates to the cure or improvability of the intellectually disabled person. Custodial accounts draw on the static nature of intellectual disability to justify continued incarceration of the intellectually disabled. Educational and improvement projects (such as the philanthropic institution and normalisation) are more likely to draw on dynamic accounts to inform their practice.

At this point, I would like to add two additional dimensions that will be useful in analysis.

Dependence/independence: The amount of care and support that the intellectually disabled person requires is an ongoing debate. This relates to the cost to society and the family at an intersection of understandings of severity and attributed (in)competence. The custodial institution is justified by claims of continued dependence and normalisation seeks to foster independence through integration in the community. This dimension is relational in nature and touches on the ethics of care and the deployment of pastoral power as discussed in chapter 2.

Competence/incompetence: The notion of intellectual disability is predicated upon individual competence. The extent to which the individual is judged to be (in)competent in social adaptation and intellectual function forms the basis for current diagnosis (American Association on Intellectual and Developmental Disabilities, 2008). In all of the above approaches incompetence is the central issue that defines intellectual disability.

Conclusion

In this chapter I have not presented a traditional history of intellectual disability as a series of ordered events and a progressive movement towards a more sophisticated and enlightened understanding of a phenomenon that was always there, waiting to be uncovered through the application of reason. Rather I have used this exploration to understand better the traces of the past that are alive in the present in the subjectification of the intellectually disabled person.

I noted the early beginnings of dividing practices in the poor house with the increasing differentiation of problematic individuals into the insane, the criminal and the idiot. The educability of the idiot becomes both a charitable and scientific concern through the philanthropic institution but these concerns are superseded by problems of populations and the species in a eugenic project. Normalisation serves as a corrective to the institutional impetus and institutes disciplinary, normalising regulation rather than removal from society. Running through these approaches are tensions between the organic/biological and the social that are configured differently but have in common an explicit or tacit acceptance of an essential organic deficit that accounts for socially observed differences. In the South African context, issues of colonialism and race further complicate the social practices aimed at addressing the problem of intellectual disability. I argue that all of these alternative constructions noted above are present in current discourses of intellectual disability to greater or lesser degrees and are reflected in educational practice for intellectually disabled people, which I shall discuss in chapter 4.

CHAPTER 4: EDUCATIONAL PRACTICES FOR INTELLECTUALLY DISABLED PEOPLE

> Of equal significance is the unexamined assumption about the taken-for-granted category of disability in educational discourse—one shaped by ideologies, history, medicine, and social and political assumptions whose central binary is ability-disability. (Ware, 2001, p. 112)

In Chapter 3, I reviewed key moments in the construction of intellectual disability as a category of disability that, as Ware (2001) notes above, is too often presented as an unproblematic entity in educational discourse. In this chapter, I undertake an exploration of educational practice as applied to the intellectually disabled person. In so doing I do not adjudicate on the best or most effective methods of education, nor do I attempt to provide a history of special education. Rather I focus on education as a particularly significant arena in which conceptions of intellectual disability arise that, in turn, necessitate or make possible certain forms of educational practice.

This discussion moves from a consideration of the ways in which intellectual disability is addressed as a general problem (see chapter 3) to the context of education. Specifically I focus on the implementation of mass compulsory education and schooling in the late nineteenth and early twentieth centuries. It was this development that created a new set of conditions within which the problem of education of intellectually disabled people had to be managed. According to Rose (1985), the introduction of compulsory education created a field for the:

> inspection and evaluation of conducts, capacities and behaviours. It created a site within which that evaluation could occur, a common standard of evaluation, a set of norms and expectations tied to the functioning of the techniques of pedagogy in the schools, and a group of agents whose daily activity depended upon the ability of individual children to display appropriate capacities and conducts. (pp.98-99)

Driven by the twin imperatives of a eugenic project (with racial overtones in the South African setting) and the focus on economic productivity, education systems had to be developed that would distinguish between those who would ultimately be useful and productive citizens and those who posed a potential drain on productivity. This called for new technologies of ascertainment and pedagogy that were grouped together within the discipline of special education. My review will not provide a chronological, comprehensive and ordered account but rather I shall highlight key points in the development of educational practices. I shall also leave aside for the present any discussion of the philosophical debates around education as my concern in this study is with practice as it relates to intellectually disabled people.

Although certain practices arose in specific historical and social contexts they leave their traces on subsequent, supposedly more progressive practices, in subtle and complex ways. The practices that I have identified as outstanding, without claiming to be comprehensive, are a) practices of exclusion, b) practices of differentiation, c) practices of special education, d) practices of advocacy, and e) practices of professionalisation and the application of expertise. I shall discuss each of these below.

Practices of Exclusion

In discussing practices of exclusion, I make a distinction between disciplinary practices that are brought to bear within mass education generally and their specific application in the South African context. The first section sets a theoretical background for the specific deployment of these practices in South Africa presented in the second section.

Disciplinary Practices of Exclusion

Foucault scrutinises the practice of compulsory education as an instance of the operation of disciplinary power. The application of constant supervision made it possible to accommodate large numbers within a classroom in such a way that:

> A relation of surveillance is inscribed at the heart of the practice of teaching, not as an additional or adjacent part, but as a mechanism that is inherent to it and which increases its efficiency. (Foucault, 1977, p. 176)

The establishment and maintenance of correct behaviour is ensured through normalising judgements that function in place of repressive forms of punishment. Foucault (1975/1995) describes the operation of this judgement as referring action to a field of comparison that not only describes but also prescribes the correct behaviour. In terms of our discussion, this could be seen as academic achievement. Within this field, individuals are differentiated from each other in terms of their value and their inherent nature. This value is measured in quantitative terms, allowing a hierarchical arrangement of worth. As noted in chapter 2, this ranking defines the difference between the normal and the pathological, establishing the normal as the regulatory mechanism for governable subjects. Armstrong (2002) notes that the implementation of mass education from the late nineteenth century in England created the conditions where children who did not conform to the prescribed ideal had to be dealt with such that: “It was against this background that an organized and structured system of special education designed to ‘relieve’ ordinary schools of difficult pupils as well as being intended to ‘meet their needs’ emerged.” (p. 451)

Erevelles (2000) sees special education as a response to “unruly bodies” whose forms of difference render them impervious to the disciplinary practices designed to inculcate the values of rationality and productivity. Their disruption of the ordered functioning of the school necessitated their removal from the learning site into special education programmes with the purpose of preserving the smooth running of schooling. In terms of intellectual disability, a group was identified who were not responsive to surveillance and who acted as markers of the outer limit of the regulatory norm. The exclusion of these was achieved through the application of the ritual of the examination, whether this was intelligence testing, behavioural assessment or classroom tests. The individual truth of these tests could be used to provide a supposedly objective measure of innate capacity which located reasons for failure or non-participation in individual deficit (Erevelles, 2000). The prescribed treatment of this group was segregation and special forms of education or care.

The need to distinguish between those that belonged in the general education classroom and those that would be best placed in special schools was the motivation behind the first tests of intelligence developed by Binet and Simon so as to effect an exact distribution of children in their appropriate educational placement (Binet, 1905). Initially only a crude distinction could be made between the normal and relatively low functioning children but the test was further refined in processes of differentiation discussed in the next section of this chapter.

Exclusionary practice is not confined to the early days of compulsory education but continues as a device to increase certainty and decrease diversity. Skrtic (2005) sees schools as normalising social institutions that construct disability as a means for ensuring conformity. He argues that in the context of increasing diversity and bureaucracy within the education system, disability gives a medicalised, supposedly objective basis for exclusion and facilitates the smooth operation of the bureaucracy. Disability, as an objective, medically defined deficit, legitimates the failure of this bureaucracy to teach children. The inclusive education movement has challenged the physical exclusion of learners categorised as disabled but has not fully undermined the logic of exclusion or taken into account the ways in which bureaucratic institutions *produce* disability. As such, exclusionary practices appear in new forms in what are supposedly inclusive settings (Slee, 2001). This will be discussed further below but I note it here as an indication of the complexity and persistence of exclusionary practices beyond physical exclusion.

Application of Practices of Exclusion in South Africa

Within the South African context, exclusion of intellectually disabled people has operated differently according to race, imposing layers upon layers of exclusionary pressures. To understand the complexity of exclusion in this context, a broader view of social exclusion is adopted following Sayed et al (2007). Exclusion is not merely about presence or absence in a particular place, but rather lack of access to socially valued processes that are designed to increase participation in economic, social and political life. For black South Africans the first layer of exclusion was from an education for participation in the political and economic life of the country.

In the colonial setting the provision of education was of a different order for the colonisers and the colonised. Kliewer and Fitzgerald (2001) note the development of sub-standard separate systems of education in the colonies set up specifically for indoctrination of the children of the colonised. A separate system existed for those of the elite who could expect to rule. The development of Bantu Education provides a prime example of this most fundamental form of exclusion within education in South Africa.

Education for black children in South Africa came under intense scrutiny (Molteno, 2006)with the appointment of the Eiselen commission in 1949-1951. Soudien (2006) examines the racial discourses in the evidence presented to the commission. Within what he terms the “race supremacist discourse” (p. 45) that came to underlie the practice of Bantu education, he presents the following quotations taken from evidence presented to the commission:

> “[The native] is … dead slow, imitative (except in terms of speed and intelligence), superstitious and primitive ... He has a tendency to sing, ... make beer. He is short-sighted, careless and stupid. His music is monotonous ... He has mainly bad

> characteristics ... It will take education, at its best, 2 000 years to bring him to the level of whites today ...' [Soudien's translation] (IS Steyn, Memorandum 73)
> • '[Despite everything] they still remain kaffirs ... Their particular characteristic is laziness ... Their social heritage is ... to have as many children as possible. It is that which stamps him as a noteworthy individual.' [Soudien's translation] (JM Potgieter, Memorandum 78)
> • '[H]e has weaker intellectual ability and ... is incapable of thinking analytically.' [Soudien's translation] (OFS University College, Memorandum 85)
> • 'His logic is negative, particularly when it comes to ideas which are European. Most cultivated habits are, in the native, still raw ... and uncontrolled. The analytic ability of intelligence of a 23-year-old is equal to that of a normal white child of about 14 years.' [Soudien's translation] (J Taljaard, Memorandum 95)". (Soudien, 2006, p. 51)

While considerably more sophisticated and humane presentations were made to the commission, Soudien argues that it is this white supremacist account that wins the day. These quotes bear a striking resemblance to the eugenic discourse of feeble-mindedness. The logic of exclusion from full participation in the affairs of the community is bolstered by recourse to the discourse of feeble-mindedness. This makes of the Bantu an object requiring the same care and protection accorded to the feeble-minded. By this logic a separate system of education is justified.

The black child who was classed as mentally defective was subject to another form of exclusion, that is exclusion from specialised services. In the early 1960s legislation was passed separately for the different race groups to bring education under the control of the different departments of Coloured Affairs, Indian Affairs and Bantu Education. The *Bantu Special Education Act no 24 of 1964* specifically addressed special schooling for disabled children classed as Bantu and expressly excluded service provision to black children with mild mental handicap (Foster, 1990). Molteno (2006) notes a paradox in that this resulted in the inclusion of black children with mental handicap into the mainstream but without any service being provided. Thus, exclusion at one level resulted in inclusion at another. However, in the context of an inferior and poorly resourced education system with no support, this did not always result in a situation of full participation.

Thus the black child was not subject to exclusion through normalising judgement but was rather excluded by means of curriculum and social stigma attached to disability. Foster (1990) attributes their exemption from normalising types of disciplinary processes, which were so evident for the white feeble-minded child, to the fact that there were numerous other mechanisms for social control of black people, such as segregation, surveillance and the stripping of land rights. I would also suggest that "scientific" evidence as to the inferiority of the intelligence of the Bantu based on extensive intelligent testing by state psychologists, such as Fick (Foster, 1990) and the conclusions of the Eiselen Commission established a tacit understanding that inferior intellectual ability was a racial property and therefore not amenable to intervention. Similarly, Erevelles (2000) notes in the United States that the logic of disability was used to underpin political and economic inequity of African-Americans.

For black children, intellectual weakness is a property of the race and therefore requires a separate education system. While this was not stated in a crude, racial form within Bantu education, Soudien (2006) points out that the use of culture as an explanation made such a racial view more acceptable without altering its impact. Physical and sensory disability remained an individual property of the person and therefore required segregation, but there was not an independent recognition of intellectual disability. For more severe intellectual disability, which necessitated extensive care and could not be seen as a racial property, there was a lack of allocation of resources for service provision for the majority of the South African population. Minde (1975) noted at the time of his writing that there were no facilities for "non-White defectives" other than for "coloureds" at Westlake.

The forces of exclusion operated differently for the white population (including to some extent the "coloured" and "Indian" racial classifications). The *Vocational Education and Special Schools Act no 29 of 1928* recommended compulsory education for all (white) retarded children up to the age of 16 in special schools or classes. This education was to be provided for a child:

> who in the opinion of the Secretary [of different departments] is capable of deriving appreciable benefit from a suitable course of action, but deviates to such an extent from the majority of children in mind, body and behaviour that he [sic]:
>
> - Cannot derive sufficient benefit from the instruction normally provided in the ordinary course of education
> - Requires special education in order to facilitate his adaptation to the community
> - Should not attend an ordinary class in an ordinary school because such attendance may be harmful to himself or other pupils in the class. (Cited in Foster, 1990, p. 56)

The operation of the normalising judgement is evident here and in fact it was especially strong with regard to the feeble-minded white child, given the concern with racial superiority. The notion of harm is redolent of eugenic discourses discussed in Chapter 3.

This Act distinguished between retardation due to remedial causes as the responsibility of the provincial education departments, and retardation due to birth defect which fell under the Union (nationally provided) education. The cut off point for distinguishing between the two was an IQ of 80. Below this point, education would be provided in special schools and would be based on the development of practical skills. Provision was also made for the care and protection of the more severely affected category of the mentally defective as the responsibility of the Department of the Interior (Foster, 1990). Thus two classes of white mentally defective children were subject to different forms of exclusion. The mildly handicapped were excluded from the mainstream and the severely handicapped were excluded from education entirely and offered care and protection in its stead. This was to undergo further differentiation with the advent of mental testing as will be discussed below.

In inclusive education debates that focus on issues of disability, it is frequently only the exclusion from the mainstream of education that receives attention, with other levels of exclusion receiving little attention. However, Sayed et al (2007) note that these debates around exclusion are becoming broader, figuring disability as but one form of exclusion. This impetus is evident in South African inclusive education policy, which will be discussed below.

Practices of Differentiation

In examining practices of differentiation, I shall first examine their origins in the development of intelligence testing and then explore their application in the South African context. Whereas the origins of intelligence testing are to be found in Europe and the United States, their application in South Africa retained many essential features while introducing a particularly racial overtone to the practice.

Differentiation and Intelligence Tests

In the application of mass education in England in the early twentieth century, the moral panic regarding the dangers of feeble-mindedness of the social reformers was combined with concerns of productivity and cost as the motivation for social action with respect to the feeble-minded. The fact that feeble-mindedness presented a danger to the population as a whole, that it required special forms of education and institutionalisation and that it threatened a drain on economic productivity made it a matter of some urgency to ascertain the existence of this deficit at an early stage (Rose, 1985). The task of the psycho-eugenic movement at this point was to forge a “link between the biological, heritable, variable basis of mental characteristics and the criteria of social worth” (Rose, 1990, p. 138) and to show how these characteristics varied across the population in a statistically normal distribution. Far from being an objective, scientific tool that reveals innate qualities, Rose (1985) describes the intelligence test as an administrative practice in support of an educational technology.

While the early practices of the intelligence test operated at a gross level to govern exclusionary practices, they soon became more refined with norms for different age levels. The test was taken up enthusiastically in the USA and in 1916, Lewis M. Terman published the first Stanford-Binet test of intelligence, which was based on the Binet-Simon, but standa(Smith, 1999)rdised on American children (White, 2000).

Terman (1916) highlighted the usefulness of the intelligence test in streamlining educational practice for the grading of the feeble-minded:

> We are beginning to realize that the school must take into account, more seriously than it has yet done, the existence and significance of these differences in endowment. Instead of wasting energy in the vain attempt to hold mentally slow and defective children up to a level of progress which is normal to the average child, it will be wiser to take account of the inequalities of children in original endowment and to differentiate the course of study in such a way that each child will be allowed to progress at the rate which is normal to him, whether that rate be rapid or slow. (¶ 1)

In addition, Terman (1916) saw a number of additional uses for the intelligence test. It could be used to identify delinquents (noting as he did “the frequent association of delinquency and mental deficiency” (¶ 14)) and even superior children. The intelligence test could further support the educational enterprise by ensuring that children were placed in the correct grades, and a future use for intelligence testing in determining the vocational fitness of its subjects was also proposed. He also extended the role of the intelligence test to a research agenda which would examine factors that influence mental development and address questions of environmental and heredity influences on intelligence. Thus the intelligence test came to be a central tool to the differentiation and classification of a previously amorphous class of individuals. It provided the tool for the normalising judgement *par excellence* as it allowed for comparison and differentiation between children and established the norm to which all must conform within a hierarchy of value. The scientific claims of the test bolstered the notion that it measured an inherent property of the individual. Sanctions could also be imposed on those who did not conform in the form of a range of exclusionary measures.

The intelligence test became an essential defining structure for what we understand to be normal or not (Rose, 1990). Within the ambit of one number a child can be graded and normalised with respect to other children. Smith (1999) likens this process of differentiation to a cartographic exercise:

> In effect, Western positivist science is driven to compare people to a standardized norm, bound by the restrictions of linear progress and unifying explanation. … In this cartography, persons with mental retardation and other developmental disabilities are described using surveying tools such as intelligence quotients and adaptive behavior measures, reflecting the authorization of statistics and numbers in modern Western culture, providing a scale for measuring its territory and serving the needs of some while devaluing others. (p.124)

Differentiation in the South African Context

In the South African context, the Binet-Simon, Terman and other tests were used in a flurry of mental testing aimed at detecting the incidence of feeble-mindedness in the early twentieth century (Foster, 1990). These tests were found to be inadequate for the South African population and it fell to Dr. M.L. Fick, the psychologist appointed by the National Bureau of Educational and Social Research, to develop relevant tests (Minde, 1975a). In the 1920s standardised tests were developed for the (white) South African population and these were applied extensively in the testing of 28 000 white children. The results of these tests informed the van Schalkwyk Commission on Mental Deficiency. A consequence of this survey was the greater differentiation of categories of mentally deficiency. This was further developed, as a result of the Van Wyk report, which informed the *Mentally Retarded Children's Training Act no. 63 of 1974,* into the classification system illustrated in Table 1.

Table 1: *Classification System Used in South Africa for Grading Mental Handicap*

IQ Range	*Grade*	*Category*	*Placement*
50-75	Mild	Educable	Special/adaptation classes and special schools
35-49	Moderate	Ineducable, but trainable	Training centres
20-34	Severe	Ineducable or untrainable	Training centres or special care, residential or day care centre
0-19	Profound	Untrainable	Special care, residential or day care centre

Note: Table adapted from Grover, 1990, p. 164.

This classification system makes the distinction between practices of education, training and care. It therefore establishes the rationale for intelligence testing as a means of discerning differing innate abilities to determine the correct educational placement, with its concomitant educational practices. In terms of Foucault’s understanding of the subject and power, the subject of schooling is objectified through a mode of inquiry (psychological testing) that operates through dividing practices that distinguish between the grades of intelligence.

Davidson and Dickman (1990) note that intelligence tests were based on problematic assumptions in South Africa. Firstly, there was an assumption that they contribute to rehabilitative processes, in which placement was the main priority. For black children few placement options existed thus negating even this limited approach to rehabilitation for the majority of the population. Secondly, the tests informing the above classification were standardised on white children only. However, the consequences of this form of classification for people with mental handicap were very real as Davidson and Dickman (1990) indicate:

> These problems notwithstanding, placement of people with mental handicap is governed by IQ scores in South Africa. People are admitted to special/adaptation classes (in regular schools), training centres, special care facilities or wards in institutions on the basis of IQ scores, sometimes obtained on a single administration of an intelligence test. This is the authors’ experience. (p. 139)

Foxcroft (1997) notes that the development of intelligence tests was racialised within apartheid South Africa such that the response to the dilemma posed above was to develop separate tests based on culture and language. Alternatively, tests developed for white people were used with norms developed for the race group to which they were applied. However, since there were many more tests available for white children, it was common practice to use these tests normed on whites and to note that the results should be "applied with caution". This caution would include qualitative assessment and the use of multiple tests. Since the late 1980s there has been pressure to develop a common test that could be used across cultures, a goal that remains elusive (Foxcroft, 2004).

The consequences of this differentiation process were, as can be expected, different for black people. While the general trend was to ignore the class of mentally handicapped black children, any extension of services to this group was undertaken within this classification. Their poor performance on intelligence tests would then expose them to exclusionary placements to a greater degree.

Practices of Special Education

Within contexts of mass compulsory education, processes of exclusion into special schools/classes or care centres were predicated upon a belief that this was in the best interests of the child. It was in this environment that the child would be able to benefit from education, largely because of the small class sizes and the specialised skills and equipment located within this setting. Exclusion from the regular school was framed as being beneficial to the child. It was not merely a case of making ordinary classrooms run more smoothly but of providing the disabled child with the "right kind" of education. A new kind of technology had to be developed for this purpose. Whereas in the case of physical or sensory disability this technology depended on adapting the environment through assistive devices and alternative communication systems, for the intellectually disabled child, the curriculum itself constituted the problem. Thus specialised attention was given to this aspect.

It would not be in the scope of this discussion to undertake a comprehensive overview of the many complex debates and the plethora of research into the most effective specialised educational technologies applied to intellectually disabled children. I have therefore chosen to zone in on the views of Professor Vera Grover since she was an enormously influential figure in South Africa in the education of mentally handicapped children, both in the fields of education and psychology. According to Grover (1990), the following principles underlie the education of mentally handicapped individuals:

1. An emphasis on social adaptation taught in real life situations including routines such as toileting and eating in the teaching curriculum.
2. A cognitive developmental approach based on Piagetian principles.

3. A detailed understanding of the child’s relative strengths and weaknesses to formulate realistic goals.
4. Freedom from the formal curriculum in regular schools, based on the teachers’ sound theoretical knowledge.

In addition she notes that the application of behaviour modification techniques has been found to be valuable.

Grover (1990) describes specific curriculum needs for the different developmental stages. She does this through a comparison between the normally developing and the mentally handicapped child. Whereas in the early years the normally developing child has intrinsic motivation to learn, the mentally handicapped child needs to be taught this, at the same time as avoiding developing a fear of failure. To this end she recommends:

> The normal nursery school model is not suitable since the child is not ready to use such a degree of freedom meaningfully. There is greater possibility of achieving the desired results by introducing short periods of highly structured finely graded, intensive individual training into the child’s daily routine which will elicit responses which can be selectively reinforced and which will ensure that success is experienced more often than failure. (p. 174)

In the middle years the normally developing child is focused on acquiring academic skills. However, since the mentally handicapped child is not expected to have the cognitive ability for this, “any attempts to imitate the curriculum and methods or goals of ordinary school are seen to be absurd and unproductive” (p. 175). Rather he or she should be exposed to a range of music, drama and art, and games can be used to develop important skills. At the heart of this approach is grading as “a step-by-step progression, always building on already well-mastered components, gradually leads the child to meet new challenges, incorporate new learning and develop feelings of self competence” (p. 175). Communication is a skill area that requires particular attention. She notes that highly skilled and qualified teachers, supported by a multi-disciplinary team that includes therapists, are best placed to deliver this curriculum.

In the senior years, the focus is on the transition from the training centre into the sheltered workshop. Some young adults might at this stage be able to benefit from limited formal learning if they have reached the necessary level of cognitive development.

This approach requires an entirely separate placement and curriculum with a focus on skills acquisition. While it draws on theories of cognitive development, this is merely to distinguish the mentally handicapped from the normal. Teaching strategies are largely behaviourist in practice, depending on reinforcement, grading and stimulus response technology. The message is that children with mental handicap learn in a qualitatively different way from normal children. They therefore require a different teaching method and this can only be delivered by personnel who are highly trained. These messages permeate the practice of special education.

In the context of the developed world (upon which special education in South Africa is largely modelled), the overall progress of special education is described as disappointing by Thomas and Loxley (2001). They argue that special education was set up as a service industry to the mainstream and it has managed to survive and grow stronger despite its unimpressive achievements. They maintain that the legacy that segregated education leaves is one of mystification of learning breakdown where the ordinary teacher feels unqualified and reluctant to deal with children labelled in some way as requiring special education.

The overall provision of special education in South Africa was examined by the National Commission on Special Needs Education and Education Support Services (Department of Education, 1997), a body set up to inform policy development aligned with the new democratic South African constitution. This report noted the strengths of special education in responding to the needs of children excluded from the mainstream because of physical, sensory and intellectual disabilities. In some cases special schools offered an enriched curriculum and they also had a significant role to play in helping learners access the curriculum through the provision of adaptive technology. Their contribution to the development of sport and cultural activities was also noted within the context of dedicated teachers and support from sponsoring bodies.

However, the criticisms of special education by the Commission include the following:

- the negative effects of large institutions in contrast to smaller, localised units of learning;
- the scaling down of the general curriculum leading to restricted career choices;
- the over-emphasis on a medical-deficit approach in the support provided;
- over-spending on specialist intervention;
- lack of facilities in rural and disadvantaged areas; and

- the fact that these centres only provide for a very small percentage of learners with ‘special needs’ to the detriment of thousands of learners who are totally excluded. (p. 21)

In response to these criticisms of the professionalised system of special education as well as the adoption of a human rights discourse of disability, practices of advocacy arose.

Practices of Advocacy

I have termed this section ‘practices of advocacy’ since the practices discussed below draw strongly on a human rights discourse to advocate for disabled people, including those with intellectual disability. I discuss mainstreaming and inclusive education separately as they have different conceptions of what these rights are and how best to achieve them to the extent that they are often framed as opposed practices.

Mainstreaming

Swart & Pettipher (2005) note that mainstreaming is the educational equivalent of normalisation. As noted in chapter 3, normalisation is predicated upon the provision of normal life experiences for the intellectually disabled person. The appeal of mainstream education is obvious since it is the normal context in which children learn. As normalisation requires the acquisition of normal behaviour as a prerequisite for participation, so too does mainstreaming. This is an approach which recognises that the disabled person should receive education in the mainstream as far as possible, within the limits set by the capability of the disabled person to “cope” in the mainstream classroom. The school is not expected to change the way that it functions and support services are not set up in such a way as to follow the child. In a well-resourced community, the opportunity to access the mainstream is earned by the disabled person who completes the necessary therapeutic hurdles. This would be the case, for example, where a deaf child with a cochlear implant, learns to talk and then attends a regular school. In less well-resourced communities mainstreaming can occur where there is no other alternative. This is referred to as “mainstreaming by default”, ‘mainstream dumping’ or ‘dump and hope’ according to Swart and Pettipher (2005, p. 7).

The relevance of mainstreaming to the education of intellectually disabled children is that it is figured as an approach where the onus is on the child to fit in as best they can. The rationale for this, based on principles of normalisation, are that it will reduce stigma, it will increase community integration and that it is the human right of the intellectually disabled person to be placed within the mainstream. However, this right is a limited one since it depends on the disabled child's ability to operate within the norms of the existing system. Participation is consequent upon the child achieving a level of competence that will not disrupt the normal functioning of the classroom and school (Department of Education, 2001). There is therefore only one response within this understanding – the application of identification technologies and placement in special schools/classes with the aim of making the child more normal until they can earn this place. Thus within a mainstreaming discourse, segregated education comes to be a logical response to the lack of fit between the intellectually disabled child and the mainstream school.

Human rights within this understanding are figured as being the right to access appropriate services. Alston (2006) provides us with an exposition of this view. He starts from the premise of the South African Constitution that all children are entitled to an education. He argues that this refers to equality of value and notes that in order for the intellectually impaired child to realise their right to dignity and freedom, they need to be provided with education fitting their ability and needs. For such children, who would require adaptation of the curriculum, he espouses a human rights view that portrays inclusive education as a violation of children's and teachers' rights. The teacher is unfairly treated by having to deal with large classes, diverse learning populations and inadequate support. His or her rights are violated within the current South African policy of inclusive education:

> Inclusive education has every possibility of making demands on the expertise and skills of a generalist teacher that s/he does not have to deal with children s/he may have in the classroom. The demands on teachers may be well beyond the level of training to the point where either a child or teacher or both may be at risk. This gives rise to the serious question as to whether a teacher could, or even should, legitimately refuse to take a class in such a situation. (Alston, 2006, pages not numbered)

At the same time, the rights of children without disabilities are violated since they will not get the time and attention that they merit from the teacher. Children with disabilities will be deprived of access to appropriate services. In this sense, mainstreaming practices make a sharp distinction between disabled and non-disabled children as separate learning groups. The child must be able to cope within the existing curriculum to earn their place in the mainstream. The problem is firmly located within the child, who has a biological deficiency, and the human rights perspective is a narrow one, primarily focused on access to specialised services. This view of human rights is largely about rights to services and sees rights as protection of one from the other. In Alston's view the rights of the intellectually disabled person to an appropriate, segregated education are compatible with other parties' rights. Their right to inclusion is incompatible with others.

Inclusive Education

With the advent of democracy in South Africa a flurry of lawmaking and policy development took place in education to serve a nonracist, non-sexist democracy within a unitary system (Donaldson, 2001). Before going into detail on the development of policy for disabled learners it is important to note that schools have gone through tremendous changes in the past 15 years, both in the demographics of their learners and the curriculum that they are required to deliver. The curriculum is based on Outcomes Based Education (OBE) that specifies the outcomes to be reached for each learning area but allows a considerable amount of flexibility as to how they are achieved. It is this flexibility that is exploited in inclusive education policy, emphasising as it does the adaptation and tailoring of the curriculum to the individual's needs in different paths to successful outcomes (Naicker, 1999).

The practice of inclusive education is aligned with the development of a social model of disability in which the disabling environment, rather than biological disability, becomes the focus of attention. It proposes that change should be directed at schools, which need to become more welcoming and inclusive through the provision of necessary support and adaptation of the environment and curriculum (Peters, 2004). Within this broad understanding there are a range of different conceptions, which deploy practices of exclusion, differentiation and professionalisation to differing degrees. I shall focus on the South African version of inclusive education, examining firstly, its origins and the resulting policies and secondly, the implementation of these policies.

Inclusive Education Policy in South Africa

The struggle for democracy in South Africa was rooted in the struggle for education and as such educational reform was at the top of the democratic government's agenda. The earliest policy documents recognise the need to address the fragmentation of the education system on racial lines and the disparities in access of the different racial groups. The topic of education support services (or what was termed psychological services) and special schooling formed part of this overall policy development process (Howell, 2000).

The National Education Policy Investigation (NEPI) was a body set up by groups concerned with educational reform in a democratic South Africa (Howell, 2000). At this early stage the need to overhaul the system for education support was recognised. Howell (2000) points out that in their understanding of special educational needs this group made a distinction between “intrinsic” deficits, based in an organic root of a physical or neurological nature and “extrinsic” deficits, arising from educational or social disadvantage. By this understanding, a staggering number of the South African school population (over 4 million) were identified as having special needs.

The policy agenda was set to provide access and equity for all South Africans. The limited provision of specialised education was concentrated in urban areas and largely limited to primary schools, with access to high school or further education being especially limited (Naicker, 1999; Stofile & Green, 2006). Given that most services for disabled children were delivered through special schools, the lower provision of special schools for other than white race groups, as illustrated in Table 2 below, was seen to be indicative of poorer service provision.

Table 2: *Provision of Special Schools in South Africa in 1990*

Race group	No. of special schools	No. of pupils in special education
Whites	89	14 969
Indians	20	5 580
Coloureds	60	6 558
Africans	71	9 811
Total	240	36918

Note. Adapted from Stofile & Green 2006, p.53

While there was an extensive process of consultation and numerous documents released on the topic of special needs education, I shall focus on two of these documents for the purposes of the present discussion. The first of these is the *Report of the National Commission on Special Needs in Education and Training (NCSNET), National Committee on Education Support Services (NCESS): Quality Education for All: Overcoming Barriers to Learning and Development*.(Department of Education, 1997) and the second is *Education White Paper 6: Special needs education: Building an Inclusive Education and Training System* (Department of Education, 2001).

NCSNET/NCESS Report.

The *NCSNET/NCESS Report* is the result of commissions appointed with the following purpose:

> The National Commission on Special Needs in Education and Training (NCSNET) and the National Committee for Education Support Services (NCESS) were appointed by the Minister and Department of Education to investigate and make recommendations on all aspects of 'special needs' and support services in education and training in South Africa. The focus of the investigation is on the development of education to ensure that the system becomes more responsive to the diverse needs of all learners. (Department of Education, 1997, p.2)

The report explicitly adopts a human rights model of educational failure that sets as its aim addressing barriers to learning and development:

> Provisions in the Constitution also ensure that all citizens, including learners who experience barriers to learning and development, have access to all other fundamental rights such as the right to human dignity, the right to equality before the law, the right to just administrative action, the right to access of information, the right to language and culture and other rights. It is imperative that in building a new system of education which will meet the needs of all learners and accommodate diversity, respect for all these fundamental rights should form the basis of all policy and legislation. (p. 34)

These barriers include physical, mental or sensory impairments as well as social disturbances, poverty and an inflexible curriculum among others. Thus no longer is the cause for failure to be sought only in the deficit in the child but rather it opens the educational and social system up for examination as well. The Commission's report adopts the social model of disability in line with the *Integrated National Disability Strategy*. Armed with this understanding, the report makes the following key recommendations:

1. There should be a single integrated education system.
2. All schools should expand their capacity to meet the needs of all children through the introduction of a flexible curriculum.
3. Learning and teaching support should be integral to the education system and reach all learners when they need it.
4. There should be appropriate human resource development to meet these requirements.

5. An appropriate funding mechanism needs to be provided that will allocate funding in an effective manner through phasing in the new approach with monitoring and evaluation (Howell, 2000).

There is a significant shift to a systemic understanding of learning break down:

> The shift away from a predominantly ‘individualistic’ approach to a ‘systemic’ approach to understanding and responding to learner difficulties and disabilities would result in the assessment of learning and other problems, including an analysis of factors in the context of the learner which contribute to the problems experienced by her/him. … Furthermore, responses or interventions emerging from this assessment would include responses appropriate to the levels at which the problems are situated. (Department of Education, 1997, p.45)

In the South African setting, barriers to learning can be at any level of the system and therefore interventions to address barriers to learning can also be at any level of the system. It is consistent with the policy to place an emphasis on supporting orphans or poverty alleviation, as a means to addressing barriers to learning. The report identifies a need for the continued existence of special schools for disabled children. At the same time these ‘specialised learning contexts’ would serve a different purpose in an inclusive education and training system:

> Specialised learning contexts would not be defined by category of disability but by the curriculum and support offered. Emphasis should be on functioning as a resource base providing consultative support to educators and withdrawal for small group learning opportunities. (p. 47)

Thus in terms of intellectual disability, the report proposes that children be educated in the mainstream depending on their support needs.

Education White Paper 6.

EWP 6 (Department of Education, 2001) is a plan for implementation that accepts the basic tenets of the NCSNET/NCESS report and fits these to departmental structures and time frames. The policy identifies six key levers for change:

1. The qualitative improvement of special schools to become resource centres.
2. The ‘mobilisation’ of 280 000 out of school youth.
3. The phased in conversion of ordinary schools to what are termed full-service schools that would be developed to meet a progressively wider range of support needs.

4. General orientation to inclusive education and training in all schools and early identification of disabilities in the Foundation Phase.
5. The establishment of district based support teams as structures that will provide support to schools, teachers and learners within mainstream and specialised contexts.
6. A national advocacy campaign around inclusive education for parents, learners, and other stakeholders.

A fundamental principle of the inclusive education policy is support, which is directed not only at the learner but also at teachers, schools and parents.

> Inclusion is about supporting all learners, educators and the system as a whole so that the full range of learning needs can be met. The focus is on teaching and learning actors, with the emphasis on the development of good teaching strategies that will be of benefit to all learners. (p. 17)

The provision of this support is to increase schools' capacity to respond to an ever-widening range of diversity. It is envisaged that this support will be provided through a departmentally mandated structure, the district based support team, which will pool local expertise to address identified barriers to learning. Special schools will be part of this team and will cater to learners with high support needs as well as acting as a resource to the district in terms of expertise in barriers to learning. Full service schools will be targeted in the initial stages as nodes for the development of within school support development (entailing human resource and infrastructure development). These schools will also serve as a resource to surrounding ordinary schools. Within ordinary schools, the institutional level support team will make use of expertise within the school community and access support from the district. The intent of this vision is to move expertise from a specific location, the special school/class, into a wider range of settings. At the same time, it aims to empower regular teachers, parents and those who fall outside of the special education profession to participate in providing support.

Practices of exclusion and differentiation according to disability type are eschewed in favour of identifying levels of support needs. The intent of this move is to focus on an examination of systemic factors, rather than individual deficit. Within this vision practices of exclusion and differentiation occur at the level of support needs rather than severity of disability. Educational provision is not made according to category of disability but rather according to the level of support required.

Differentiation also applies to the curriculum. In contrast to the development of a separate and appropriate curriculum tailored to the child's needs, the same curriculum applies to all children. It is adapted by ordinary teachers with the support of structures such as the institution level support team and the district based support team.

As a public policy EWP6 cannot be perceived as neutral in its intent. Peters (2007) notes:

> Every written policy document deploys a particular discourse as both tactic and theory in a web of power relations. (p. 100)

Van Rooyen and Le Grange (2003) unpack some of these power relations in a deconstruction of EWP6 and identify a 'business discourse' that is concerned with cost-effectiveness that drives toward self-sufficiency of the objects of the policy in an attempt to reduce the fiscal burden that they pose in their dependent state. This then leads these authors to consider whether inclusion may be constructed as too expensive and therefore not feasible for implementation. They also identify a 'pioneering discourse' that constructs an ambiguous position for special schools. The exclusionary pressures exerted by special schools are not acknowledged despite the portrayal of separation and exclusion as "decadent and immoral" (p.11). This leads van Rooyen and Le Grange to question the central role of special schools that are to be strengthened rather than abolished and to ask whether this discourse reflects in the implementation of the policy.

A voice at the margin of the 'pioneering discourse' is that of inclusion before the development of inclusive education policy in what is termed "inclusion by default" or "maindumping" (p. 11). The experience of learners who attended regular schools in spite of disability and reported positive experiences within rural communities is ignored.

Thus it is only once the inclusion process is brought under the monitoring and control of the experts that it really counts as inclusion. The power/knowledge implications are clear. The disabled child is constructed as an object for inclusion through the disciplinary procedures of the 'experts', often members of the psy-complex or the medical profession. This will be further discussed under the section on professionalisation below.

Implementation of Policy.

In the implementation of the policy up to this point, the material effects of these discourses can be detected. Firstly, the Department of Education itself notes with concern the growing enrolment in special schools since the publication of the policy:

> There is an increasing number of learners being unnecessarily referred to special schools from their local mainstream schools. In the space of three years (2004 to 2007), the number has increased by more than 15 000 learners (from 77 752 to 93 000). (Department of Education, 2008, p. 6)

The rapid increase in the numbers of pupils in special schools and the number of schools belies the inclusive intent of the policy and perhaps indicates an overemphasis on the development of special schools as compared to the other key levers of change identified in *Education White Paper 6.*

Wildeman and Nomdo (2007) examined implementation at a provincial level where the responsibility lies for enacting the policy. They note the slow progress of implementation and attribute this to the following:

1. The policy was not properly funded, depending largely on donor funding.
2. A shared understanding of inclusive education has not been established, both within the implementing directorates of the Department and between other stakeholders who are deemed to be essential, for example parents.
3. There was a lack of educational provision and planning for out-of-school youth who were identified but could not be accommodated.
4. There has been an *ad hoc* development of district based support teams which operate very unevenly within and across provinces.
5. Policy implementation for inclusive education has been isolated from mainstream development. This relates specifically to the location of inclusive education in the directorates concerned with special needs rather than as a transversal policy across all directorates.

The professionalisation of inclusive education within a medical model of disability is also evident in the difficulty encountered with a move toward the social model. Engelbrecht (2006) notes that despite the commitment to values of inclusivity that are evident within education policy making, the changes in understanding of, and behaviour toward, difference within the school and classroom setting remains a challenge. She states that the development of over-arching policies is insufficient to address traditionally entrenched discourses around difference.

Practices of Professionalisation and the Application of Expertise

The role of the professional in the differentiation processes described above is central. It is the professional who measures, grades and informs decisions of educational placement, which have far reaching effects for the individual so classified and placed. Considerable power therefore lies with the professional in determining what was good for the child. This process is highlighted in chapter 2 with reference to the exercise of psychological expertise. The conventional history of special education as the progressive development of knowledge and expertise obscures the operation of this power and renders families and classified individuals invisible. I therefore adopt a more critical perspective that examines the effects of professional practices.

As I have noted above, the process of differentiation specified different locations for different categories of mental handicap. Whereas the medical profession laid claim to the work of the custodial institution, psychology gained a firm foothold in the field of education in large measure due to the technology of the intelligence test. The zeal with which Cyril Burt (in Great Britain) and Terman (in the United States) approached the task of bringing education under the discipline of psychology, was matched by that of Dr. Fick and his colleagues in South Africa (Rose, 1985; Foster, 1990). What happened after placement was then the domain of teachers and therapists in the specialised settings. The role of the psychologist in special education was largely to identify mental handicap in all its forms and to prescribe placement. Once the child was placed in special education or care, their role was minimal, largely supervisory or that of consultant (Barton, 1997). However, the physical absence of psychologists from the special education classroom does not imply the absence of psychological expertise. This expertise bolsters the authority of the special educator (both relative to the parents and to the regular educator) such that they are in possession not only of scientific and technical knowledge but they also carry ethical weight by virtue of their knowledge of the best interests of the individual (see chapter 2). The regular classroom teacher is barely visible in the process, despite the fact that he or she would frequently report the initial signs of failure.

Practices of professionalisation have been heavily criticised within a social model of disability (see chapter 2) for medicalising disability, and resistance to the authority of the medical gaze forms a corner stone of disability activism. In the case of intellectually disabled people in education systems the effects of professionalisation and the application of expertise have been described for regular educators in the mainstream and for parents of these children. I shall discuss each of these below.

Expertise and Regular Educators

The early exclusion of problematic children from the mainstream and the subsequent development of the discipline of special education has rendered the teaching of such children as an extraordinary skill that is not encompassed within the general tenets of sound pedagogy as it applies to the "normal" child (Schoeman & Schoeman, 2002). The regular educator is lacking in the special skills that are required to teach a certain class of children – those that are classified as disabled in some respect. Should they be required to teach such children they will require training and support from professionals with the requisite expertise (Department of Education, 1997, 2001). In the absence of such training, the requirement that they teach the full range of learning needs can, in some views, be seen as an abuse of their rights (Alston, 2006). The lack of expertise in the regular school introduces the element of conditionality on the participation of disabled learners in the mainstream. The participation of disabled children in regular schools is conditional on capacity building aimed at ensuring the requisite levels of expertise.

Within this frame, the pressure for exclusion remains potent even where supposedly progressive practices of inclusive education are implemented (Slee, 2001). The practices of expertise are grounded in a medical, positivist understanding of disability that sets it as a thing apart, a property of an individual that requires special knowledge (Reid & Knight, 2006). Only the expert has the deep, penetrating knowledge of this form of difference from which they are able to exercise authority over educational decision-making.

Expertise and Parents

The exclusion of parents as decision-makers for their disabled children is noted in chapter 3, grounded in the knowledge of experts about the nature of intellectual disability. In the process of professionalisation, the voices of the experts came to carry more weight than those of the family. An early expression of this is found in Binet (1905):

> The organization of methods is especially important because, as soon as the schools for subnormals are in operation, one must be on his guard against the attitude of the parents. Their sincerity will be worth very little when it is in conflict with their interests. If the parents wish the child to remain in the regular school, they will not be silent concerning his intelligence. "My child understands everything," they will say, and they will be very careful not to give any significant information in regard to him. If, on the contrary, they wish him to be admitted into an institution where gratuitous board and lodging are furnished, they will change completely. They will be capable even of teaching him how to simulate mental debility. One should, therefore, be on his guard against all possible frauds. (¶ 8)

The above passage is instructive as it pits the objective truth of the child's capability against "parents' interests". The best interests of the child are a matter of objective truth to which parents do not have access as they lack the deep knowledge of the professional.

Within the context of education in South Africa, parents are encouraged to become involved in the education of their children and EWP 6 specifically promotes a collaborative approach between parents and teachers in addressing their children's needs (McKenzie & Loebenstein, 2006). This is expressed as the desire for partnership between parents and professionals. However, the intuitive, subjective knowledge of the parent is no match for the disciplinary powers of the professional, especially when it is couched in the language of the child's best interest (McKenzie & Muller, 2006).

In the absence of service provision, parents have come together in support of human rights for their disabled children (Howell, et al., 2006). Thus there are organisations such as Down Syndrome South Africa (DSSA), Disabled Children's Action Group (DICAG) and Autism SA among others that promote the rights of their members. Their practices of advocacy vary considerably with the major thrusts being toward inclusion in education (DSSA, see McKenzie & Loebenstein, 2006) and broader claims to social justice and human rights for disabled children (DICAG, see Howell, et al., 2006). The degree to which either special schools or inclusive education are advocated for by parents' organisations depends to a large degree on the functionality of the regular education system in their community and the degree of poverty with which they have to contend. However, the need for more expertise, whether this is training teachers in regular schools or building new special schools, is a recurring theme.

Conclusion

The discussion above serves to highlight significant practices in the education of the intellectually disabled person. Practices of exclusion arose within the context of mass education in order to facilitate the smooth process of developing productive citizens. Provision for intellectual disability came later than physical and sensory disability, reflecting doubts about the viability of any such education. The configuration of intellectual disability as an organic deficit of the individual for white children and as a racial/cultural property for black children also impacted on provision. The beginnings of special education were predicated upon the need to identify and divide in order to provide for separately.

Devised as a tool for making gross distinctions between those who could be educated within compulsory schooling and those who required separate provision, intelligence testing came to be used for the greater differentiation of pupils in schools. It was justified on educational and economic grounds as a predictive tool that could prevent wastage through the early identification and proper treatment of defect or even exceptional talent. Differentiating practices constituted a powerful mechanism for establishing the norm as a defining principle of worth in the education system. IQ scores formed the basis of educational placement decisions in the South African context. The application of the technology of the test enhanced the power of the professional with respect to parents through its supposed objectivity in informing the 'right' decisions for the child. In the South African context the use of the IQ test as an instrument for buttressing racial inferiority claims has been noted.

The subsequent adoption of human rights discourses with respect to disability created an impetus to integrate intellectually disabled children into regular schools. This took two different forms. The first, mainstreaming, was based on a service provision model of normalisation. The second, inclusive education, drew on claims to equality and human rights for all within a non-racial democracy.

The move toward inclusive education is firmly adopted within the South African policy framework. Within this view the learner may experience barriers that are organic or social, with organic barriers being associated with disability. The organic is mediated through social process in line with the social model of disability and contributes to disability insofar as the needs created by the organic deficit are accommodated. This is achieved through systems of support. In the absence of support, participation in the mainstream is construed in a negative light as ‘main-dumping’.

Practices of professionalisation are predicated upon the notion of expertise and the impact of these practices on both parents and regular educators was noted. The lack of expertise in the regular school sets inclusive education up as a process of capacity building in the regular school, in the absence of which it is not fair to include disabled children in the mainstream. Parents are excluded from decision -making about their children because of their lack of knowledge about the truth of intellectual disability.

Thus far in this thesis, I have located intellectual disability within a theoretical framework and explored representations and educational practices with respect to intellectual disability through the lens of critical disability studies. My task now is to identify discourses of representation and education in the specific context of Buffalo City and examine how these discourses are deployed in the light of my theoretical framework and the literature that I have reviewed. In Chapter 5 I shall present the methodology used to examine representation and educational practice within the context of Buffalo City, South Africa.

CHAPTER 5: Q-METHODOLOGY AS A METHOD FOR ANALYSING DISCOURSES OF REPRESENTATION AND EDUCATION OF INTELLECTUALLY DISABLED PEOPLE

> We had been, for some time, looking for a way of explicating – locating, identifying and describing – the multiplex of accounts, understandings, representations and policy positions we assumed were there to be found in effectively any aspect of collective life one cared to focus upon. In Q we discovered such a means for exploring a whole plethora of images, ideas, debates and explanations. (R. Stainton Rogers & W. Stainton Rogers1990, p. 4)

> Inherent in the philosophy behind the method (Q-method) is that no one understanding is superior or objective. The approach is particularly suited to exploring topics where a particular discourse has tended to dominate other available viewpoints. (Bryant, Green, & Hewison, 2006, p.1190)

In planning this research I sought a methodology that would provide a technique to expose multiple ways of understanding intellectual disability and its concomitant educational practice. I noted that the dominance of a biomedical discourse around the topic obscured many different and equally valid understandings of the topic (see chapter 2). I was thus persuaded, like the authors quoted above, to utilise Q-methodology for my purpose. It is a technique that they have found useful in exposing a diversity of views that are often obscured by dominant discourses. My examination of representations of intellectual disability and educational practices presented in chapters 3 and 4 convinced me that there are a multitude of discourses operating in this complex field. A simple linear progression toward an ultimately enlightened understanding of intellectual disability and increasingly effective educational practices does not fit the reviews that I presented. Rather it is the deployment and dispersal of discourses, some contemporary and some apparently long since discarded but with powerful traces in the present, that constructs the object of intellectual disability and the intellectually disabled subject. In this chapter, I explain why my choice of methodology is relevant to the research questions I have posed and how it was implemented in the study of education of intellectually disabled people.

I shall begin this discussion by reviewing my theoretical framework with respect to Q-methodology. In this discussion, I shall look at post-structuralism as a starting point. I shall then focus on the major thrust of my theoretical framework – a critical disability studies approach. In order to make the link between this theoretical framework and Q-methodology it will be necessary to explicate in detail the particular understanding of the method that I adopt, with specific reference to how the methodology can be used with different conceptions of discourse, subjectivity and the understanding of the pattern analytic factors that result from application of the method. This discussion will allow me to locate my theoretical position explicitly within these debates. Once the link between method and theory is established, I shall then focus on the application of Q-methodology to the current research.

Post-structuralism

As discussed in chapter 2, the theoretical framework of this study aligns itself with a broad post-structuralist view that rejects the possibility of viewing intellectual disability as a fixed entity ‘out there’ in the real world that can be objectively defined and measured. Rather intellectual disability is understood as being located within social practice and subject to the power relations that construct knowledge as truth. This is not to deny the materiality and very real consequences of intellectual disability, some of which are ameliorated through useful biomedical applications. It would be unhelpful (mostly to intellectually disabled people themselves) to argue away forms of impairment that severely restrict the individual’s ability to participate in society in the absence of supports and adaptations. However, it is also to recognise that impairment is always-already imbued with social meaning and cannot be viewed in a natural, unmediated way. That is to say, the impairment, not only the disability, is contingent on cultural, historical and social meaning at any one time or place.

In the case of intellectual disability, biomedical accounts have claimed the status of truth and hence have silenced other alternative conceptions. Wendy Stainton Rogers (1996) notes how the biomedical discourse is granted the status of : “‘fact’, in contrast with the status of ‘belief’ accorded to all other forms of knowledge” (p. 73). The objects of the biomedical discourse are given status as things in the world, such as ‘intelligence’ or ‘social adaptation’. However, Q-methodology has the potential to disrupt this claim, firstly by identifying alternative discourses, and secondly, by treating them as epistemologically equivalent to each other.

The truth status of the biomedical discourse is built on the adoption of a scientific method that is based in hypothetico-deductive thinking, which proceeds by fixing a concept, such as intelligence, *a priori*, theorising about the object and then instituting various measures or tests to ascertain whether the object varies as predicted or not (Watts, 2002). However, in a post-structural approach the object of study is not defined as a fixed entity at the start of research. Rather it is viewed as a contested and constructed entity. Through the research process of this study, a sophisticated, nuanced and discourse-based understanding of intellectual disability and associated educational practices will be configured from the available ways of speaking in the social context of the study. The chosen methodology should be able to tell us: “What is this thing called intellectual disability?” and “What are the understandings of educational practice for this category of person?” as understood by members of the culture who make use of available ways of speaking, knowing and acting. I shall now give an overview of the method before highlighting how it is applied differently according to distinct theoretical frameworks and aligning my approach with critical disability studies.

Q-methodology and Critical Disability Studies

The methodology used in this study is Q-methodology. It was originally developed by William Stephenson, a researcher in the psychological laboratories of Spearman and Burt in the United Kingdom in the 1920s and 1930s. In this section I relate Q-methodology to critical disability studies by providing a brief overview of the method, identifying two schools within this method and locating my current research within the debates between these schools in a way that is consistent with my theoretical approach.

The innovations that Stephenson proposed were two fold:

1. The data consists of subjective rankings of items through what he termed ‘self-reference’.
2. The data is analysed in terms of *whole patterns* of responses, rather than looking for similarities and differences between individuals in performance across items or tests (Kitzinger, 1999, p. 267).

Each of these aspects will be discussed below.

Stephenson termed the methodology Q in order to distinguish it from what he called R methodology. In R-methodology the person is tested with respect to a pre-defined concept and their score is ranked relative to other people’s scores. R factor analysis identifies grouping of highly inter-correlated tests or variables. In so doing it attempts to reduce visible variation of phenomena by proposing an underlying, invisible cluster of variation, a factor (S.R. Brown, 1980). An R methodological factor tells us simply that a particular group of variables have displayed a similar pattern of variation in a certain population. Subsequent individuals can be tested against this abstraction to see how they differ from each other with respect to it. This has become intimately associated with the individual differences tradition of psychology as it tells us about variation across a population of persons with respect to their performance on a test measuring this latent variable (Stenner, Watts, & Worrell, 2008).

The data for Q-method, on the other hand, consist of sorting patterns of relative and subjective evaluations of carefully selected items (usually but not always statements). In most Q studies a different person creates each pattern; but sometimes people sort on two or more occasions (for example, as ‘me as I am’ and then ‘me as I would like to be – these are called different ‘conditions of instruction’). Each sorting pattern is treated as a single, gestalt entity for analysis. Q-method aims to maximise the expression of qualitative variation and to record it in numerical form so that it “makes qualitative variation mathematically tractable” and in so doing “The qualitative dimension shifts from being ‘noise’ to ‘signal’” (Stenner, et al., 2008, p. 216).

The process of conducting a Q-study has been variously described in the literature (see S.R. Brown, 1980; S.R. Brown, 1997; R. Stainton Rogers, 1995; Watts & Stenner, 2005) as a pattern analytic technique that can be used to study: “..ordered patternings of cultural understanding” (R. Stainton Rogers, 1995, p. 180). While there is a fair degree of agreement on what Q-method is, what it can achieve and how to conduct Q studies, there are two key areas of dispute between what are, effectively, two “schools” of Q theorists and researchers. One, led by Professor Stephen R Brown in the USA, takes a “scientific study of subjectivity” (SSS) position; the other, originating from the UK with Rex and Wendy Stainton Rogers as key proponents, views Q research as a means to conduct research within a social constructionist framework and as a form of discourse analysis (DA). I shall use the acronyms SSS and DA to refer to these approaches in further discussion.

The general area of disagreement concerns the location by the DA school of Q-methodology within post-structuralist, discursive methods and within critical psychology. I shall engage with this aspect in order to explicate the relevance of my chosen methodology to my theoretical framework and research questions. I shall therefore present below a fairly standard and non-controversial account of the method before moving into a discussion of some of the theoretical debates that concern my current study. After that, I shall explain the application of Q-methodology to my study of the education of intellectually disabled people.

The Q-methodological Study

The terms used for the application of a complete process of Q-methodology is a Q-study. It involves the following steps:

1. Delineation of the concourse and the selection of the Q-set,
2. Selection of participants,
3. The Q-sort,
4. Statistical analysis,
5. Factor interpretation.

Each of these will be discussed below.

Delineation of the Concourse and the Selection of the Q-Set.

The starting point for a Q-methodological study is the assumption that every topic or concept has its own concourse that contains all that it is possible to say about this topic. William Stephenson defines the concourse thus:

> A universe of statements for any situation or context is called a *concourse*, and refers to conversational and not merely informational possibilities, and is arrived at empirically for every concept, every declarative statement, every wish, every object in nature when viewed subjectively. (1986a, p. 37)

Thus the concourse for intellectual disability consists of all that can be said about this topic, whether it be factual (informational) or informal knowledge (conversational), providing a field of investigation that locates subjective views (in Stephenson's understanding of subjectivity, which will be discussed further below) in an observable domain – communication. Curt (1994) describes the concourse as "the bounded universe of possible elements … from which … discourses are configured" (p. 90). The concourse for any one topic is diverse and multi-voiced but remains bounded because it is located within place and time in terms of what it is possible to say or do. The concourse itself is situated within a "field of communicability" (Stephenson cited in Watts & Stenner, 2003b, p. 159), which can be seen as the universe of discourse on all topics that is culturally available to social actors in a particular cultural or sub-cultural location.

The Q-methodological study thus starts with an attempt to delineate the concourse relating to the topic under study. First of all, the concourse is surveyed by drawing on a whole range of documents, academic and lay, public and private as well as making use of different media-resources and interview data. For example, Barry and Proops (1999) make use of interviews and academic and popular literature in their study of environmental policy. Bryant et al. (2006) draw on focus groups, interviews, data from previous studies, information pamphlets, academic literature and websites to examine accounts of Down Syndrome. It is not clear from the literature how the limits of the concourse are set, but Stenner et al. (2008) note that the researcher should gain a familiarity with the topic. Rex Stainton Rogers (1995) likens the process to preparation for a questionnaire or a thematic analysis. He emphasises the need to draw on the researcher's own cultural knowledge.

From this concourse, the researcher then proceeds to spend considerable time noting down and building up a body of statements that, as far as possible, express the full range of "what can be said" about the topic. From this large body of material, a sample of statements is then selected with a view to achieving adequate representativity of all culturally possible perspectives on the topic.

The final stage in the selection of the Q-set is where the researcher identifies a much smaller sample of statements (this needs to be of a manageable size for people to sort – usually between about 40 and 80 statements). The aim is to arrive at a set of statements (the Q-set) that is representative of the diversity and range contained within the concourse and which is manageable for participants to engage with in a sorting task (Watts & Stenner, 2005).

Selection of Participants.

The participants are not chosen to reflect a representative slice of the population on various criteria. Participants are rather selected purposively in such a way as to reflect the range of diversity that is anticipated in the discourses under study. Sampling is strategic insofar as it:

> typically places its Q-sets [the research instrument of Q-methodology] in a multiplex of person-locations or subject-positions, ones where the researchers expect, through their own cultural knowledge, to hear varied stories, accounts or discourses. (R. Stainton Rogers, 1995, p. 182)

The guiding principle for the selection of participants is that of "finite diversity" (R. Stainton Rogers, 1995, p. 182). The participants are selected to reflect diversity in their accounts, but it is not anticipated that this diversity will be endless. Rather it is expected that there will be several distinct accounts in play. In Q-method just one person who patterns their responses to express a particular account will be sufficient to substantiate the existence of the type (R. Stainton Rogers, 1995).

The Q-sort

The participant in the study is presented with the statements in the Q-set and is requested to position him or herself in terms of a specific condition of instruction, (such as ‘most strongly agree with’ and ‘most strongly disagree with’) with respect to each statement. This task takes the form of a ranking procedure where each participant slots each item in the set into a specific ranking point. Usually the response pattern takes the form of a forced quasi-normal distribution. (Brown, 1997; Watts & Stenner, 2005). The purpose of the quasi-normal distribution is to ensure that participants engage with the data in a thoughtful way as well as facilitating the statistical analysis. The forced distribution does not appear to affect the factors which emerge, since distribution effects are virtually nil (Watts & Stenner, 2005). It is merely a pragmatic device that aids data collection and yields equivalent patterns for all (R. Stainton Rogers, 1995).

This procedure yields a pattern of responses — termed the Q-sort — that is then subject to statistical analysis. The ranking task is supplemented by demographic information and responses by participants to open-ended questions. The purpose of collecting these open-ended statements is to aid interpretation of factors that are identified by the study (Watts & Stenner, 2005).

Although the researcher selects the statements, he or she does not seek to predict the way in which the statements are patterned through the different actions of the different participants. The patterns of meaning are derived through the participants’ actions upon them. Participants construct their own meanings, since a specific statement is not assumed to have a fixed meaning independent of the pattern in which it occurs. Within a post-structural framework, meaning is created (and created differently) through different readings of the statement in question. Hence meaning only becomes apparent through the patterning of items that emerge as the person engages with the set of statements (R. Stainton Rogers, 1995; Watts & Stenner, 2005).

Statistical Analysis

The statistical technique employed in Q-methodology is a by-person correlation and factor analytic technique. The overall configurations obtained from the sorting tasks are each correlated with every other sort. Thus, the initial correlation matrix reflects the relationship of each Q-sort with every other Q-sort. This matrix is then factor analysed to produce a set of factors onto which participants load according to the configuration of their individual Q-sort. Dedicated computer software completes this part of the process, allowing data input, generating the initial matrix and making processes of factor extraction and rotation straightforward. Within Q-methodological studies centroid factor extraction techniques are preferred, because this technique does not yield only one statistically correct answer, as would be the case with a principal components analysis. The centroid technique yields an infinite number of solutions, which are all mathematically correct. In this way the decisions of the researcher come into play rather than a purely mathematical process (Stricklin & Almeida, 2004). This level of indeterminacy provides greater latitude for the researcher to address specific theoretical concerns while not changing the data as such. For further elaboration, S. R. Brown (1980) provides a detailed discussion of the technical aspects of factor extraction.

The output of the factor analysis is a range of factors, each representing a reduction of data from the individual Q-sorts configured by the participants. Factor rotation simplifies the factor structure so as to make factors distinct from one another and therefore make interpretation easier and more reliable. This can be achieved through Varimax or judgemental (hand) rotation but Varimax is generally the “house standard” according to R. Stainton Rogers (1995, p. 188). The best estimate of the factor is derived from a weighted average of the Q-sorts according to their loading on to the factor. This maximises the amount of variance explained by the extracted factors by ensuring as far as possible that loadings are “large on one factor and trivial on the other” (p. 187).

While it is possible statistically to have a huge range of patterns, the principle of finite diversity and the constraints on what it is possible to say or do within any one time or culture means that a limited set of factors can be expected to be suitable for interpretation, although there is some debate as to how these factors are selected and described. The researcher is thus faced with the decision about how to demarcate which factors merit further analysis. The DA school (R. Stainton Rogers & Stainton Rogers, 1990) of Q-methodology accepts a larger number than the three or four suggested as standard by Stephenson (1986b). Criteria for interpretable factors will be discussed in the methodology for the current study.

Each factor is represented by a factor array which indicates a score for each item/statement arrived at through a procedure where the scores of the most significantly loading Q-sorts are weighted higher than those of others on the factor. The factor array takes the form of an idealised, individual Q-sort constructed from the aggregation of closely related Q-sorts rather than reflecting any one individual’s sorting pattern. In this sense it is inter-subjective rather than subjective, reflecting a particular account or, in my emphasis on the role of language, a discourse.

Factor Interpretation

Interpretation of factors is not well described in the literature (Kitzinger, 1999) but usually it begins with an analysis of the extreme poles of the factor array and then moves toward more neutral scoring statements. Through consideration of within-factor variation and comparisons with other factor arrays, a narrative, summarising account of each factor is built up (Curt, 1994). Apparent contradictions and confusions are considered in the light of the open-ended comments of the respondents as well as their biographical details. Where there is difficulty in interpreting the factor, the researcher can go back to participants loading onto the factor and seek clarification. Generally, a name is given to each factor that is descriptive of the orientation that it illustrates. Theory and literature is also brought to bear on factor interpretation (R. Stainton Rogers, 1995; Watts & Stenner, 2005).

Q-methodology and Critical Approaches

Having presented an outline of Q-methodology, I shall now engage with some of the debates that arise when the method is placed in the context of post-structuralist, critical disability studies as argued for in my theoretical framework. The position that researchers take on these issues has fundamental implications for the nature of the understanding that is produced through the application of the method. I shall discuss the following issues:

1. The relationship of the field of communicability and the concourse to discourse
2. The understanding of subjectivity and the self
3. The status of factors

The Relationship of the Field of Communicability and the Concourse to Discourse

Watts and Stenner (2003b) provide an extensive discussion of Stephenson's understanding of the concourse and identify different readings of the concept between the so-called DA and SSS schools of Q-method. They argue that the conception of the concourse put forward by Stephenson relies on an understanding of the concourse around any particular topic as being devoid of normative force. In this reading of the concourse, the individual is free to choose and make meaning from his or her own perspective:

> Stephenson's cultural/psychological field is hence reduced to the status of a passive *reference library* — a mere repository of shared knowledge — which individual persons can accept or reject with *complete freedom,* on the basis of their own *perspectives of existence.* The participant is under no pressure to conform or to uphold any *normative* standards of understanding or behaviour. (Watts and Stenner, 2003, p. 162).

In this understanding there is a clear divide between culture (available discourse) and subject (individual persons), which places the subject as the active constructor of meaning. However, within a post-structuralist framework we have noted the constructive effects of discourse. Discourse is *productive* in the way that it constructs the subject (who in turn has constructive effects on discourse) and constrains or permits action in certain ways. The operation of discourse is saturated with power/knowledge and cannot be distinguished from a supposedly neutral concourse in terms of productive power. I follow Watts and Stenner in the recognition of the effects of what they term a "cultural field" but which I would rather term the conditions of possibility, within a DA understanding of Q-methodology:

> Our understandings, imaginings, the stories we tell, the accounts we find plausible, the nature of our interactions, and so on, are all shaped by the pre-existent narrative and conceptual structures of our cultural field or *pool of information.* (Watts & Stenner, 2003b, p.168)

The Understanding of Subjectivity and the Self

Stephenson promoted Q-methodology as a technique for the study of subjectivity by scientific, operant means. His aim in undertaking such a study was to include within the domain of psychology those experiences that reflect individual subjectivity. Given that these experiences are not amenable to direct investigation he proposes rather to focus on the overt activity of "conscriring", whereby subjective views are placed in the domain of the social and thereby become amenable to investigation:

> The theory of subjective communicability (Stephenson, 1986a) dispenses with consciousness and its various surrogates as "non-essentials" replacing them with what

> is “essential”, namely, *conscriring*, the “sharing of knowledge”. (Stephenson, 1982, p. 240)

In this sense, his approach represents a turn to language, or more broadly and in his own terms, communication, as the object of study. This reflects the turn to text within critical psychology approaches as well as a decentering of the self (Henriques, et al., 1998). However, the extent to which subjectivity is a property of the individual, on the one hand, or a cultural construction, on the other, is at issue between the SSS and DA schools of Q-methodology (cf. S.R. Brown, 2003; Good, 2003; Watts & Stenner, 2003b). The issue at stake relates to the understanding of the inner (subject) and outer (culture) relationship. Watts and Stenner (2003a) argue that the SSS school, by following Stephenson in this respect, is led into the position of accepting the agency of the individual self as prior to, and the originator of, social action. A corollary of this perspective is that factors identified through Q-method come to be seen as reflective of individual subjectivity as in more or less stable points of view or attitudes, that is they are phenomena existing “in the head”. In contrast, the DA school of Q describes factors as accounts or discourses that reflect culturally available ways of talking and acting with respect to social phenomena without the compunction to situate these understandings within individuals. In adopting this perspective, I follow Wendy Stainton Rogers (1998):

> we view factor analysis as “merely a tool” — not as a means of revealing some psychic “essence of subjectivity” but as a convenient technique for gaining access to the way ideas, arguments, explanations and representations may be “knowledged into being”. (p. 11)

As such I am concerned with the views of the participants only to the extent that they provide an account, which can be interpreted and located within a social context. It is not the aim of this study to identify points of view of intellectually disabled people or their teachers or their parents. Rather it is to understand better what discourses are deployed and with what effect in the education of intellectually disabled people. In this respect it is the construction of subjectivity within a dynamic of power and resistance as effected through discourse, rather than individual subjectivity or consciousness that is the object of study.

The Status of Factors

The status of a factor in Q-methodology varies across different applications of the method. What does a factor represent? An electronic database search on EBSCO Host in the Academic Premier database yielded 105 abstracts in a search of studies using Q-methodology. These studies used a multitude of terms for the factors. These included: *forms of identity, accounts, discourses, types of world view, beliefs, styles, constructions, choices, characteristics of the user* and many more besides. I do not intend to provide an analysis of the positions that these naming practices might reveal but only to highlight that there is indeed a huge range of understandings of what a factor is — a range worthy of a Q-study in itself! Given this diversity I feel that it is important to be explicit about what my view of a factor represents. In particular it must be placed within the context of discourse.

The statements that are presented in the Q-set are texts, which are organised in coherent and regular ways through the process of Q-sorting. Q-methodology is a pattern analytic tool that reduces the data from individual Q-sorts of the statements provided in the Q-set through identifying regularities across multiple Q-sorts by means of the pattern analytic technique of factors analysis. In chapter 2, I noted that texts are more than language and include a range of artefacts that can be given "interpretive gloss" (Parker, 1990, p. 193). I consider the factors to require further interpretation noting with Parker (1990a) that: "We have to bring a knowledge of discourses from outside onto any example or fragment of discourse for it to become part of a coherent system in our analysis" (p. 192). This accords with the practice of the DA schools of Q-methodology where it is noted that the initial description of a factor must be complemented "by a more thorough cultural analysis" (Curt, 1994, p. 125). Thus factor descriptions need to be distinguished from discourses. Further analysis is required to situate these accounts within the discursive context of representation and education of intellectually disabled people in Buffalo City. This is achieved through an examination of the discursive context in which representation and education of intellectually disabled people takes place.

The various accounts are not viewed as a fixed property of one individual or of a group of individuals who could be clustered together as a type or category of persons. The Q-method factor can be viewed as part of a cyclical process of discourse analysis in which the participants and researcher play more, or less, salient roles in determining what is analysed and how. This cyclical process can be represented in the form of successive steps:

1. The delineation of the concourse can be seen as the first discourse analytic step, which draws from culturally available ways of doing or saying. This can be through the direct involvement of participants of the Q-study, where the Q-set is derived from participant interviews and the same participants sort the statements (such as in

Kitzinger's (1985) study of lesbianism). It can also be indirect where the concourse is drawn from a wide range of textual sources. For example, Bryant et al. (2006) include data on previous studies and interviews, which may include the Q-study participants or others assumed to have important similarities to the study participants. The researcher's role is to draw the line as to what is deemed relevant.

2. The selection of Q statements for the Q-set involves a form of thematic analysis, where discursive themes that can be expressed through particular statements are delineated from the concourse. This is most often carried out by the researcher alone (but see Billard (1999) for alternatives that include participants more in the process).
3. The participant takes centre stage in the ranking of statements in a Q-sort. As they pattern the statements within the Q-set, they are working with statements to fashion available discourses into useable patterns.
4. The researcher then relies on quantitative analysis through the use of a statistical software package to reduce the variation presented by the participants. The objective, quantitative position adopted here is enriched by the researcher decisions made in factor rotation, which have an impact on the ultimate factor structure.
5. In the analysis stage the researcher is the main "giver-of-meaning" to the data through describing and interpreting the factors. The participants can be involved in elucidating and supporting factor interpretations. At this stage, the researcher's view of discourse as descriptive or constructive will determine the level to which the description of factors goes.
6. The constructive effects of discourse require, in my view, a further level of analysis where the researcher brings a range of cultural knowledge to bear upon factor interpretation and aims to foreground the power/knowledge effects of different discourses. This interpretation of factors is researcher led again but allows the opportunity to draw on other texts and practices to relate factors to textual and social practices outside of the factors delineated. In this respect the interpretation employs the analytic of tectonics described by Curt (1994) which seeks to understand how power and knowledge is constructed through this interplay. Wendy Stainton Rogers describes Q as a method of discourse analysis insofar as it is used to:

> gain insight into what is being "knowledged into being. Our primary concern is to find out about the purposes to which the text …is being used: what ideas are being peddled? What ideologies are being promoted? What is being covered up and who is being silenced? Who gains and who loses? (1998, p. 12)

In terms of my theoretical perspective, these questions are framed as the conditions of possibility that constrain and produce the intellectually disabled subject within educational practice. It is this application of Q-methodology, which looks at the interplay of discourses, that marks out a critical, political agenda for Q-methodology as opposed to a liberal pluralist approach that treats all accounts as merely expressions of different points of view (R. Stainton Rogers, 1995; W. Stainton Rogers, 1998). The epistemological equivalence of discourses does not imply that there is a moral or political equivalence of different discourses.

While recognising the inextricable relationship between representation and practice, I have adopted within Q-methodology an analytic that teases out what Curt (1994) terms different “moments” of discourse. I shall make an explicit distinction between representation of intellectual disability and the practices of education of people so categorised, using this as an analytic tool to highlight the mutually constitutive nature of the way we understand a type of person (a “human kind” in Hacking’s terms (1999, p.34)) and the practice that is followed or is deemed to be desirable. I take this approach not because these “moments” of discourse are separate but rather for the opposite reason — they are intimately related and it therefore becomes important to examine the interaction between them (Curt, 1994). The effect of this distinction is threefold:

1. It recognises that the objects of discourse that are constructed through representational work are deployed in particular ways in social practices. Thus, for example, the biomedical construction of intellectual disability enables certain practices (such as assessment) and disallows others (such as independent decision-making).
2. This distinction serves to tease out the different processes involved in *knowing* an object from the proper *associated practices accorded* that object. This distinction undermines the taken-for-granted information — the ‘facts’ about intellectual disability — that construct obvious and desirable forms of action. Once the representational work is revealed as contingent and socially determined, the obvious course of action can also be interrogated with respect to the effects that it achieves.
3. The distinction acknowledges that representations, images or portrayals of a category of individuals seem to be more resistant to change than policy development toward this group. As Curt (1994) puts it: “As new stories are told around old

> representations, new flesh may be formed on the bones of the old, but the bones themselves go marching on, and remain archivally accessible" (p. 93). The persistent marginalisation of intellectually disabled people, despite the development of progressive policies that aim toward inclusion in society, bears testimony to the enduring "bones of the old".

Thus, for the purpose of this study the constructive effects of discourse for the intellectually disabled subject are unpacked through a methodology that distinguishes between different "moments" of discourse in representation and practice.

The Application of Q-method in the Current Study

In the previous section, I have outlined my reasons for using Q-methodology in this study and noted my specific orientation to the method. In this section, I present the application of Q-methodology in the current study of intellectual disability. I shall begin by showing how the methodology will be used to address my research questions before moving on to a detailed description of the application of the method in the current study.

Research Questions

My first question is:

1. What discourses are deployed in the representation of those identified as intellectually disabled in Buffalo City, South Africa?

In order to address this questions I developed Q-set A, which was drawn from the concourse of statements used in representation of intellectual disability. I carried out four Q-studies with this Q-set. The participants were drawn from three groups – intellectually disabled adults, parents of intellectually disabled children or adults and professionals working with intellectually disabled people. The studies for each of these groups were done separately and formed Q-studies A1, A2 and A3, as noted in Table 3.

Table 3: *Number of Q-studies and Participants in Each Study for Q-set A*

Q-study	Q-set	Participants
A1	A	22 intellectually disabled adults
A2	A	30[1] parents of intellectually disabled children or adults
A3	**A**	33 professionals involved in education of intellectually disabled people
A4	A	Factors derived from Q-studies A1, A2 and A3 as Q-sorts. (See below)

Q-studies A1, A2 and A3 were analysed separately resulting in the identification of 14 factors. Q-study A4 includes all of these factors in a second-order study as a summarising and comparative exercise, resulting in four factors. This study is what is termed a second-order factor analysis (Watts, 2002) and it makes use of the factors derived from Q-studies A1, A2 and A3 as the Q-sorts, which are then subject to factor analysis. I chose to undertake these two levels of analysis in order to pay detailed attention to the accounts of the different groups. As has been noted in chapters 3 and 4 the accounts drawn on by non-professionals have been dominated by the discourses of expertise. However, due to the variability of these accounts, I have not described them as discourses but rather refer to them as accounts and only refer to them in the discussion in chapters 8 and 9 where there is a particular point of interest to be noted. The factor descriptions that resulted from Q-study A4 were considered to be a coherent summary of the component studies (A1, A2 and A3), yielding what I would term discourses in the critical framework that I have adopted.

My second research question is:

2. What discourses are deployed concerning the practices of education of those identified as intellectually disabled in Buffalo City, South Africa?

In order to address my second research question I developed Q-set B drawn from the concourse on education of intellectually disabled children in the Buffalo City district. This study included 63 participants, 31 parents of intellectually disabled children or adults and 32 professionals involved in education of intellectually disabled people. Intellectually disabled adults were not included in this study because of the complexity of the research instrument

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[1] While there are 30 participants, there are 31 Q-sorts due to the fact that I, as the researcher, completed two Q-sorts.

and the research task (this will be discussed further below). From this study, six factors were identified for interpretation as discourses of education of intellectually disabled people.

My third question is as follows:

3. What are the effects of these discourses in constructing the intellectually disabled subject and associated educational practice?

The analysis of the factors identified in the first and second questions is based on an analytic that separates "moments of discourse" into representation and practice. My third question examines how the interplay between these discourses of representation and practice support each other and delineates areas of contestation between different discourses. In order to do this I make connections between representation and practice on conceptual grounds and through reference to demographic information of the participants. I shall explain the research methodology for the current study in detail below.

Research Method

In this section, the detailed research method for the current study is presented taking into consideration the following:

1. Participant sampling.
2. Generation of the Q-sets: Item sampling.
3. The ranking procedure: Q-sorting.
4. Statistical analysis.
5. Interpretation of the factors (Watts, 2002).

Participant Sampling

Given the notion of a finite diversity of views, sampling of participants is directed at ensuring that the range of views is represented through their selection. The selection of participants is theory driven to the extent that variation is seen to be distributed across any given population (Robbins & Krueger, 2000). Participants are selected who seem, on the basis of the researcher's knowledge of the topic, to provide access to distinctive points of view. I, as the researcher, consider myself to be qualified in this respect, having worked in the field of education for disabled children for over 20 years as a researcher, teacher trainer and community facilitator. I also have personal experience as the mother of an intellectually disabled child. From this experience I have noted that parents, intellectually disabled adults and professionals can be expected to approach the issue of education from different angles. It was for this reason that three groups of participants (for studies A1, A2 and A3), who were anticipated to draw on different understandings, were identified. I also made every attempt to gain a diversity of racial groups since in the South African context the significance of race cannot be ignored. However, a caution is made here that the selection of participants is not intended to allow for extrapolation of a particular discourse to racial, disability or gender categories. Rather these dimensions of diversity are traced as they interact in the deployment of discourses in particular enabling or constraining contexts.

It was noted that the expression of the views of intellectually disabled people themselves is an important consideration of a disability studies approach (see chapter 2) and therefore ways were sought to ensure their inclusion. Informal networking on the Q-method list reveals that Q has been used with intellectually disabled people with some success. Wolf (personal communication, 25 July 2007) noted that working with intellectually disabled adults was a rewarding experience in her study of the views of sickness and invalids' benefit clients in a Q-methodological study in New Zealand. The participants were grateful for the opportunity to participate and they appeared to engage in a satisfying manner with the Q-sorting exercise. Van Exel (personal communication, 18 July 2007) noted in his research that Q-methodology was a useful and rewarding tool to use in planning services for intellectually disabled people and found it helpful in accessing the rarely studied views of intellectually disabled people. In order to ensure genuine expression within the methodology the views of intellectually disabled people must be included in the concourse and the Q-set. In addition, the Q-sorting process should be accessible to intellectually disabled people. The demographic details of participants for each of the studies is described below.

Q-study A1.

The definition of intellectual disability used for participant selection was a recipient of services directed toward intellectually disabled people. However, the participants were also given the opportunity to self-identify. Six identified as having an intellectual disability, seven reported a physical disability, five said they had a disability but were not sure how to describe it and four reported no disability at all. Twenty-two participants were selected through the assistance of the following organisations:

1. Down Syndrome Association Amathole. This is a local branch of a national organisation, Down Syndrome South Africa, which aims to support people with

intellectual disabilities and their families. Parents of intellectually disabled children and adults run the organisation.

2. McClelland Adult Centre for the Intellectually Impaired, a residential centre for intellectually disabled adults with a sheltered workshop on the premises. The workshop also caters for non-resident adults.
3. Parkland Special School. This is a special school for learners with intellectual disability that is run by the Eastern Cape Department of Education. It is housed in brand new, state of the art buildings in a suburb of East London, Beacon Bay. It was developed as a merged entity from two schools —McClelland School and Parkside Centre. The learners and staff come from a diverse range of racial groups.

These organisations provided the names of adults who met the criteria set for intellectual disability and whom they felt would be competent in the sorting task. They were then contacted individually to request interviews and set a time, place and date for the interview. Some requested the presence of their parents during the interview and others did not specify. At McClelland Centre no parents were present as the interviews were conducted at the centre. All of these participants were based in Buffalo City. My previous experience in the field ensured trust and cooperation.

The participant sample displayed the following demographic characteristics:

Ages: Ranged from 18-60 years, with an average of 32 years and a standard deviation of 11.83 years.

Gender: 11 males and 11 females.

Race: 17 participants were white, three black and two coloured

Employment: 11 participants were employed in a sheltered workshop, 8 in the open market and 2 had no employment.

The racial composition of this participant group was largely white. The reasons for this are mainly due to the language issues. The pool of black intellectually disabled adults who would have sufficient command of English to complete the Q-sorting task appeared to be very small on investigation. If a Xhosa translation had been available this issue could have been addressed but it was not within the scope of the current study to develop such a translation.

Q-study A2.

Parents of children and adults who were identified as being intellectually disabled (either because they received their education in a special school for intellectually disabled learners or because they were placed in sheltered employment or hostel facilities for intellectually disabled people) were the participants in this Q-study. This consisted of 30 parents who were recruited through:

1. Down Syndrome Association Amathole.
2. Canaan Care Centre, a day care centre that describes itself as “a safe place for brain injured children”. It is privately funded through donations.
3. REHAB Organisation for Persons with Disabilities, founded in 1997, when the Societies for Mental Health, Physical Disability and the Blind disbanded to form one organisation to provide an integrated service to all people with disabilities and to extend services to the rural areas.
4. Parkland Special School.

As for Q-study A1 these organisations provided me with names of parents whom I then contacted to arrange individual interviews (occasionally two were interviewed at the same time). All were based in East London and were selected to reflect a range of diversity on the following dimensions:

1. Age of child.
2. Inclusive or segregated employment or educational settings for their child.
3. Race and language groups.

As the researcher and a parent, I did a repeated Q-sort with both Q-sets. My own Q-sorts therefore account for two of the participant sorts, thus making 31 Q-sorts available from 30 participants. This was both to make explicit my location as a researcher (S. Brown, Undated; S.R. Brown, 1997; Curt, 1994) and to explore any changes in perspective that I might have undergone through the research process. This will be discussed in the results section.

Demographic information on the participants is as follows:

Ages: Ranged from 27 to 64 years, with an average of 43 years and a standard deviation of 13. 6 years.

Gender: 22 female and 8 male.

Race: 15 participants were black, 14 were white and one was coloured.

Employment: Seven participants worked in administrative positions, one in sales, two in outreach to disabled people, six were self-employed, two were teachers, four were in medical professions, and eight were unemployed.

Q-study A3.

The 33 participants in this study are professionals who work with intellectually disabled people. They include psychologists, teachers in ordinary and special schools, district officials and a medical doctor. Participants were recruited from:

1. Parkland Special School (six participants). This school was described for Q-study A1.
2. Khayalethu Special School (five participants). This is a special school for children with intellectual disability. It falls under the Eastern Cape Department of Education. It was previously, under apartheid, a school for black children and continues to serve this population exclusively. Similarly the staff is all black. It is much less well-resourced than Parkland Special School.
3. Inyathi Primary School (four participants). This is a primary school in Duncan Village, one of the poorest areas of East London. The staff have had little or no training in inclusive education and operate under difficult conditions. For example, they have large classes and the toilets at the school have been out of operation for an extended period.
4. Ebotwe Full Service School (four participants). This school has been identified as the full-service school for the district. As such teachers have been trained in inclusive education and the school is being upgraded physically to meet a wider range of learning needs (see chapter 4 for an explanation of full-service schools). It is situated in Mdantsane, a formerly black “township” of East London now incorporated in the municipality of Buffalo City.
5. Hudson Park Primary School (two participants). This school previously served white children only and now caters for all races. However, the composition of the staff, which is largely white, does not match the diversity of the student population. Both of these participants have had some experience in teaching intellectually disabled children in the mainstream.
6. Members of the district based support team (two participants). This team is a critical support structure for inclusive education and includes a range of education support staff and district officials (see chapter 4).

7. Staff from REHAB (four participants) involved in inclusive education projects.
8. Practitioners in private practice (two participants) who deal with disabled children and support their parents in making educational decisions.
9. The director of Canaan Care Centre (one participant).
10. Past and current Masters in Education students at the University of Fort Hare and Rhodes University (three participants). Their current research was not focused on education of intellectually disabled children.

Permission was sought and gained from the East London Education District Manager (see Appendix A) to interview teachers and district officials in the East London education district. I wrote a letter to these schools, with a copy of the district director’s consent attached (see for example, Appendix B), requesting their participation and offering to visit them to arrange suitable times. Interviews were then set up by the school principals at the schools’ convenience, in such a way as not to disrupt learning and teaching activities. Similarly interviews were arranged with the district officials. Additional teachers beyond those at the designated schools participated as individuals outside of the school jurisdiction but were aware of the district director’s consent. For those professionals who worked at REHAB the consent of the organisation’s director was sought and gained. The private practitioners gave their own consent. I received enthusiastic cooperation from the schools and the individual participants. Interviews were arranged in advance telephonically with an explanation of the nature of the research, the time it would take and the kind of task that it entailed. The demographic information for this group of participants is presented below.

Ages: Ranged from 30 to 61 years, with an average of 44 years and a standard deviation of 7.8 years.

Gender: 29 female and four male.

Race: 17 participants were black, 12 were white, three “coloured” and one Asian.

Employment: Seven participants were teachers in special schools and 12 in regular schools. There was one teachers’ aide from a special school. Four principals, three of them from special schools or centres, and one from a regular school participated in the study. Three participants were psychologists (two of these were district officials). There was one medical doctor, two therapists and one inclusive education consultant. There were also two community development facilitators.

Q-study A4.

As noted above Q-study A4 was a second order study. Thus there were no direct participants in the study. The factors that were entered as Q-sorts in this study derived from the participants in Q-studies, A1, A2 and A3.

Q-study B.

For Q-study B, the same participants as for Q-studies A2 and A3 completed the task. In Q-study B there are 63 Q-sorts (62 participants, see above) rather than 64 as expected if all participants from Q-studies A2 and A3 took part in Q-study B. This is because one of the participants in Q-study A3 (a black, female teacher at a regular school) declined to complete the second Q-sort due to another pressing engagement. This was her prerogative as agreed upon in the consent form. As noted above, intellectually disabled adults did not complete the second Q-sort due to the complexity of the material and the sorting task. I believe that a different methodology, which I have not been able to explore here, would be better suited to eliciting the very important contribution that this group would make to discussions of education for intellectually disabled people.

As a token of my appreciation to the organisations (not individuals) that arranged interviews, I made a small donation to their running costs and assisted with networking opportunities. Their participation was not dependent on this as they did not know about it prior to making arrangements. At Khayalethu Special School I was invited as a guest speaker for a school function, a duty that I was happy to perform.

Generation of the Q-sets

Two different Q-sets were developed and these were selected from different, but overlapping, concourses of statements:

1. Q-set A concerned the representation of intellectually disabled people in response to a general question: “What do you think an intellectually disabled person is like?”
2. Q-set B concerned the practice of education for intellectually disabled people in response to the general question: “What do you think about education for intellectually disabled people?”

The concourse for each of these Q-sets was delimited with consideration to sampling what it is possible to say and do with regard to any social phenomenon (Stenner, Watts, & Worrell, 2008). In my view, care needs to be taken to avoid replicating dominant accounts and ensuring that the concourse will be sufficiently broad to allow culturally devalued accounts to be identified. For the purposes of addressing the research questions a comprehensive development of the concourse was called for. However, it could include all that there is to say and do on the topic. For example, the views of severely and profoundly intellectually disabled people were not accessible to the researcher at this point due to practical and time constraints. These did not form part of the concourse and therefore did not feature as an option in the ranking procedure. Furthermore, this category of persons did not undertake the ranking task due to the intellectual barriers that the task poses. While constitutive discourses about this category can emerge through the patterning process, discourses of resistance that might be deployed by this group will, most likely, be absent. I recognise this as a limitation in the current study and see it as a future research direction. The precise delineation of the concourse for this study will be elaborated on below.

Although there were two different concourses for the different Q-sets, there was an overlap between the documents used in each concourse. As Eden, Donaldson and Walker (2005) point out, the delineation of the concourse is not a simple task and is extremely time consuming. I had the advantage in the current study of being immersed in the field of education for intellectually disabled people for most of my working life. I was therefore able to identify salient accounts and documents that should be included in the concourse.

A major concern was with setting criteria as to whether the concourse is sufficiently complete. I followed the approach of Eden et al. (2005), which was to draw on grounded theory principles by attempting to reach a saturation point where statements start to be repeated. In addition completeness was sought in a deliberate and focused effort to ensure that accounts originating from marginalised groups, specifically of intellectually disabled people, women and black South Africans are represented in the concourse. The range of documents used is presented below with specific details provided in Appendix C.

1. Transcripts of interviews already conducted by myself and co-researchers for Inclusion International (II), which is a global federation of family-based organisations advocating for the human rights of people with intellectual disabilities worldwide (://www.inclusion-international.org/en/index.). Permission was granted to make use of these transcripts by the lead researchers.

2. Transcripts of interviews already conducted for an evaluation of Disabled Children's Action Group for Norsk Forbund for Utviklingshemmede (NFU) in 2006 by co-researchers and myself. Permission was granted to make use of these transcripts by the lead researchers.
3. Documents within the public domain including a) policy documents, b) South African text books that deal with education of intellectually disabled people, and c) media reports on intellectual disability from the local newspaper (the *Daily Dispatch*) over the past three years.
4. Literature review conducted in chapters 3 and 4 of this study
5. Presentations and reports from intellectually disabled self-advocates for Inclusion International, all of which appear in the public domain

By sifting through these documents I developed two separate sets of statements from which to draw the Q-sets. There were 205 statements for Q-set A, and 300 for Q-set B. I then proceeded to cut down the number of statements. Unfortunately, as was noted by Eden et al. (2005), there is not a great deal of guidance in the literature on how specifically to approach this task and I developed my own procedure utilising pointers from the existing literature. These were:

Step 1: I reviewed each concourse and eliminated statements that were in direct repetition.

Step 2: Themes were identified for each Q-set, using a thematic analysis as a preliminary procedure to feed into a theoretical model aligned with discourse theory and Q-methodology. As such I engaged in the following process based on the procedure described by Braun and Clarke (2006), leaving out the more analytic processes as these are undertaken in the application of Q-method. Firstly, I familiarised myself with the statements through repeated readings and noted down initial ideas at each reading. I then grouped the statements, generating initial codes and applying codes to sets of data that cohered together in a systematic fashion. From here, I proceeded to collate codes into potential themes.

For Q-set A, the following themes emerged:

1. (In)dependence.
2. Family vs. state responsibility.
3. (In)competence.
4. (In)visibility.

5. Static or dynamic nature.
6. Issues of voice and identity.
7. Exclusion/inclusion.
8. Qualitative difference vs. quantitative difference.

For Q-set B, the themes were as follows:

1. Individual issues.
2. Parent issues.
3. Community issues.
4. Departmental/management issues.
5. School issues.
6. Teacher issues.
7. State level/policy/economic issues.
8. Care vs. education.
9. Nature of the curriculum for intellectually disabled people.
10. Segregation and inclusion and degrees in between.

Step 3: The statements in each of the themes were reviewed again for repetition and positive and negative versions of the same proposition. They were adapted in consideration of Rex Stainton Rogers' (1995) criteria in the following manner:

1. Balance — the statements were sorted for a balance between positive and negative and neutral propositions. This is in order to give sufficient opportunity for participants to populate the *most agree* to *most disagree* continuum.
2. Intelligibility and simplicity — these aspects were especially important for intellectually disabled adults and were addressed by attempting to use simple clear language.
3. Appropriateness to the issue — consideration of the theoretical framework and the research questions ensured a focus on relevant information.
4. Comprehensiveness — a sufficiently wide range of statements, reflective of the finite diversity of the concourse should be addressed without repetition occurring.

Through this process, Q-set A was reduced from 205 to 133 statements. Q-set B was reduced from 300 to 228.

Step 4: Both Q-sets were presented to a range of experts, one an expert in Q-methodology, one in intellectual disability and two in education of children with disabilities. Their comments guided further adjustments with regard to Rex Stainton Rogers' (1995) criteria above. At this stage, the decision as to how much to change the statements from their original form had to be taken. While there is recognition that statements should be replicated as closely as possible to their original occurrence, there was also the need to meet the demanding criterion of intelligibility for intellectually disabled adults in Q-set A. Most reviewers expressed concern about the complexity of the material for Q-set A. At this stage the number of statements was reduced to 40 for Q-set A and 80 for Q-set B with a balance sought between simplicity and comprehensiveness.

Step 5: Piloting of the sets developed in Step 4 was undertaken with two intellectually disabled adults for Q-set A and with five professionals and parents for Q-sets A and B. This indicated that for Q-set A the language and ranking procedure needed to be simplified but the content was found to be useful and comprehensive. The conversion of the statements to a simpler and easy read format was commissioned. An organisation based in the United Kingdom, Inspired Services, converted the statements, the letter of information, the consent form and the task instructions into an easy to read format that incorporates both clear and understandable language and the use of pictures to aid understanding. This modification was applied only for the intellectually disabled adult group.

In terms of Q-set B, it was noted that it was too long, particularly since the participants were required to do both Q-set A and Q-set B in the same sitting. Reduction in this case was achieved by going back again to the research questions and removing more peripheral issues. These were largely from the State *level/policy/economic issues* and the *Departmental/management issues*. The language used in the statements also had to be adapted somewhat to meet the needs of English second language speakers.

As a result of these steps, two Q-sets were developed, Q-set A with 40 statements presented in two formats (the easy to read version with pictures and the text version) and Q-set B with 60 statements. Each statement was printed onto a laminated card that could be moved around as the participant deliberated on the ranking of the statement for his or her own Q-sort. These complete Q-sets are presented in chapters 6 and 7 in a discussion of the findings.

The Ranking Procedure: Q-sorting

The procedure will be discussed below in detail for Q-set A and additional information for Q-set B will then be provided.

Q-set A.

S. R. Brown (1980) states that Q-sets of 40 statements or less can safely use a scale of +4 to – 4. From the pilot study with intellectually disabled adults it became apparent that this was too complex and a simpler than usual ranking system was required. Watts (personal communication, 6 March, 2008) warns against a scale that is too simple since there will not be room to express difference and Q-sorts will therefore correlate with each other very highly. He suggests a compromise of a 7-point scale (from +3 to-3), which was ultimately adopted. The compromise was made in order to include intellectually disabled adults. The finding of statistically significant factors in all studies suggests that there was sufficient expression of variation.

The responses were grouped in a quasi-normal distribution that is illustrated in Figure 1.

Figure 1: *Numbers of Responses that Participants Can Make at Each Level of Dis/Agreement for Q-set A*

-3	**-2**	**-1**	**0**	**1**	**2**	**3**
[4]						[4]
	[5]				[5]	
		[7]		[7]		
			[8]			

Note. The numbers in square brackets at the bottom of each column indicate the number of statements that should be placed in each column. Thus for-3 and +3 there should be four statements in each column and for 0 there should be eight items.

In line with Stenner et al. (2008), items, each printed on its own card, were sorted by participants and moved around and exchanged until their best expression was obtained. The participants were then asked if there was any change that they would like to make before the statement numbers were recorded into the matrix provided. Intellectually disabled adults completed the task in a one on one situation with the ongoing support of the researcher in terms of reading, writing and comprehension of the sorting task. This was based on a relationship of trust and allowing plenty of time for responses.

Each participant was given an extra page where they could comment on any single one of the statements if they wished. In addition, they were asked, orally, their reasons for choosing the items that they agreed with or disagreed with the most. They were also asked to express their general understanding of intellectual disability after completing the Q-sort. These comments were used to support factor interpretation.

Participants with intellectual disability were given the explicit instruction:

> *"There are many people with disabilities. Some people have a physical disability. Some people cannot see well. Some people cannot hear. Some people have an intellectual disability and have difficulty in learning. I want us to talk about people who have an intellectual disability, like the people in this picture. People say many things about people with intellectual disability. We have written down some of the things people say about people with an intellectual disability. Please read or listen to these. For each one please tell me if you agree, disagree or don't know. I will then ask you to decide which ones you agree with more than others and which you disagree with more than others."*

These instructions and the statements were presented orally in the easy read format including pictures for the intellectually disabled adults. See Figure 2 for an example of the statement cards. Inspired Services, based on their experience with intellectually disabled adults in the UK, recommended the use of pictures (http://www.inspiredservices.org.uk/). In the selection of the pictures they paid attention to diverse representations according to race age and disability. They recommended the use of line drawings as being easier to understand than photos.

Figure 2: *Example of easy to read version of statements*

15. They can have a long-term relationship or get married

The ranking procedure was carried out in one to one personal interviews. Where the participant was unable to read the interviewer read the statements for him or her. Sometimes further explanation was required both for those who could and could not read in such a way as to encourage the participant to make their own judgement. Interviews were conducted in the residential facility at McClelland Centre for the Intellectually Impaired, at the participants' homes and in coffee shops or places of work. All of the participants were very keen to participate and all gave consent after a detailed explanation of the purpose of the study (see letter of information in Appendix E).

A consideration for Q-study A1 is that the respondents themselves have been classified in some way or another (either through attending special school or being in sheltered employment or residential placement) as having an intellectual disability. However, they were not asked to complete the Q-sort from their own position but rather to express their views on intellectual disability in general. This was done in order to ensure that statements that might seem derogatory or stigmatising when applied to oneself can rather be seen as "what some people say". There was no requirement to identify personally with these statements.

There were some difficulties encountered in the Q-sorting process with intellectually disabled adults, including the following:

1. Inability to read the statements (only about half of the participants were literate). I overcame this by reading to them and explaining the meaning in as neutral a fashion as possible.
2. Tendency to focus on the picture provided. This only applied to some participants who felt that they were commenting on the picture rather than the statement. This was very difficult to counter and fortunately was only evident in two cases.
3. Difficulty with rating one statement above another. I overcame this by going through the statements one by one saying: "Do you dis/agree with this a lot or a little?" and then sorting them into piles until they fitted into the forced distribution.

However, the analysis derived is sufficiently coherent and convincing to demonstrate that the technique was used effectively to gain accounts of intellectual disability from intellectually disabled adults (see chapter 6).

Participants from the professional and parents' groups were given the following instructions:

> *"On these cards I have recorded statements that people make about people with intellectual disability. Read these statements and sort them into three piles – one pile for those statements you agree with, one for those you disagree with and one for those about which you feel neutral, do not know or feel would need some sort of qualification before you could state your views. Once you have done this I will ask you to sort them into the ones you agree or disagree with more than others. There is no right or wrong answer. I am interested in your own point of view."*

For the parents, interviews were conducted at their homes, at the Down Syndrome Amathole offices or at REHAB, according to whichever was most convenient for them. Professionals were interviewed at the schools, in their offices, homes or coffee shops as requested.

A completed grid is illustrated in Figure 3 below. The numbers in the first and last rows indicate the level of (dis)agreement from -3 to +3. This was the same ranking system as used for intellectually disabled adults so that the Q-studies would be comparable.

Figure 3: *A Completed Q-sort Entered Into a Grid.*

-3	*-2*	*-1*	*0*	*1*	*2*	*3*
Strongly disagree	*Disagree*	*Disagree somewhat*	*Neutral, do not know*	*Agree somewhat*	*Agree*	*Strongly agree*
2	5	4	1	12	14	15
10	6	9	3	19	21	18
16	7	13	11	20	22	25
33	8	17	24	23	28	35
[4]	40	26	27	30	29	[4]
	[5]	34	32	31	[5]	
		36	37	39		
		[7]	38	[7]		
			[8]			

Note. The numbers in square brackets indicate the number of statements that are required in each column. Numbers in the remaining cells indicate the number of the statement that is placed in that position. The order of numbers in the column has no significance.

Q-set B.

In Q-set B the complexity of the ranking procedure was less of an issue as this did not include intellectually disabled adults. I made use of the 13-point scale for 60 items in line with recommendations made by S. R. Brown (1980). This is illustrated in Figure 4 below.

Figure 4: *Numbers of Responses that Participants Can Make at Each Level of Dis/Agreement for Q-set B*

-6	**-5**	**-4**	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**	**+5**	**+6**
[2]												[2]
	[3]										[3]	
		[4]								[4]		
			[5]						[5]			
				[6]	[6]		[6]	[6]				
						[7]						
-6	**-5**	**-4**	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**	**+5**	**+6**

Note. The numbers in square brackets at the bottom of each column indicate the number of statements that should be placed in each column. Thus for -6 and +6 there should be two items in each column and for 0 there should be 8 items.

The statements for each Q-set were printed and laminated and cut up into cards with one statement per card.

The instructions for this task were as follows;

> *"On these cards I have recorded statements that people make about the education of people with intellectual disability. We will do the same task as we did with the first set*

> *of cards, except that there are more cards in this set and you will have more choices about how strongly you agree or disagree with the statements. Read these statements and sort them into three piles – one pile for those statements you agree with, one for those you disagree with and one for those about which you feel neutral, do not know or feel would need some sort of qualification before you can state your views. Once you have done this I will ask you to sort them into the ones you agree or disagree with more than others. There is no right or wrong answer. I am interested in your own point of view."*

Q-set B was completed in the same interview as Q-set A except in one case where we were not able to finish in one session and the second set was completed at a later date. As for Q-set A, participants were asked to explain their reasons for the statements that they agreed with the most and those that they disagreed with the most and to express their general understanding of education for intellectually disabled people. They were also encouraged to note any comments that they might have on a separate page or ask the researcher to note them down.

All participants were given a letter of information about the research and asked to sign a consent form if they agreed to be interviewed, which they all did. Most were extremely helpful and cooperative. They engaged seriously with the task and found it valuable and thought provoking.

Statistical Analysis

Each individual Q-sort was entered into PCQ for Windows (Stricklin & Almeida, 2004). An initial correlation of each Q-sort with every other Q-sort was performed and a centroid factor analysis was applied to the correlation matrix. While there are many debates about the usefulness of hand or judgemental rotation as opposed to the mathematically motivated Varimax rotation, I shall not enter into the debate here but rather refer the reader once again to S.R. Brown (1980) for a detailed discussion. For my purposes, I followed Watts (2002) in choosing a factor rotation solution that maximises a) the amount of variance accounted for by the factor and b) the number of Q-sorts significantly loading onto factors. Factors were subject to Varimax rotation with additional hand rotation to maximise the number of participants loading onto factors and the amount of variability accounted for by the factor solution.

The “strength” of a factor in terms of the percentage of variance that this factor accounts for is of limited significance for the following reasons:

1. Participant selection does not claim to be representative of the entire population. Thus it would be making too strong a claim to assume that the factor strength (as evidenced by the amount of variation it accounts for) represents a position that is descriptive of the general population.
2. The intention of this Q-methodological study is not to identify the *strength* of the factor but rather to identify the *range* of accounts that are available. As such each factor is equally significant from a theoretical perspective. The significance of the factors is not a function of its statistical weight (Kitzinger, 1999).

The factors that were selected for interpretation were chosen on the basis that they have an eigenvalue in excess of one and each factor had at least two Q-sorts loading onto it. The eigenvalue is the sum of squared factor loadings onto that factor. As such it is a guide to the amount of variance that a factor accounts for. An eigenvalue greater than one indicates that the variance accounted for by that factor is greater than can be accounted for by any single Q-sort (S.R. Brown, 1980; Watts & Stenner, 2005). In the case of bipolar factors, where participants load either positively or negatively onto the same factor, thereby representing *opposite* views to each other, a criterion of one participant loading was accepted (see discussion of bipolar factors below).

The sorts that load significantly onto a factor are termed factor exemplars (Stenner, et al., 2008). All Q-sorts loading onto the factor are merged into one interpretable best estimate, which resulted in a score in each factor for each item (R. Stainton Rogers, 1995). The software does this automatically. In producing the merger of factors greater weight is given to the Q-sorts with higher factor loadings since they are better approximations of the factor being loaded. At least one item must be assigned to every ranking position (Stenner, et al., 2008; Watts & Stenner, In press). Confounded Q-sorts that load onto more than one factor are excluded from the weighting procedure. The output of the statistical procedure is when each factor is represented by its own best estimate Q-sort or factor array (Watts & Stenner, 2005). The factor array presents the items/statements that cluster together in a significant way with a rating score for each factor. This is the data that is then subject to interpretation in a more traditionally qualitative manner.

A further useful output of the statistical analysis is the identification of consensus and distinguishing statements. Consensus statements are those that achieve statistically significant agreement across all the factors within a Q-study. As such they indicate areas of agreement between the factors and such statements are not very discriminatory. On the other hand, distinguishing statements serve to highlight rankings within a factor that are statistically different from the rankings given in other factors within the same Q-study. These distinctive statements provide a useful key to interpretation as they highlight the way in which any one factor differs from others in the Q-study.

For Q-study A1, a six-factor solution was adopted as accounting for the highest percentage of variance with significant factors. Factor A1.2 in this study, is bipolar, with each loading reflecting the opposite account of the other. Thus they are in fact, two separate factors with only one participant loading onto the factor. In this case the theoretical interest of retaining these factors with only one significant loading overrides the above stated criterion of at least two loading participants for a factor (S.R. Brown, September 8, 2008). For Q-studies A2 and A3 the same procedure of orthogonal varimax rotation and hand rotation was followed, resulting in six factor and five factor solutions respectively.

Q-study A4 is what is termed a second order study. In this procedure, the factors that were identified in the three studies A1, A2 and A3 are entered as individual Q-sorts and a factor analysis is performed on these factors. This is possible because the same Q-set (Q-set A) and the same ranking scale (+3 to – 3) were used for all the participants in each of the three groups. The bipolar factors from Q-study A1 discussed above were excluded from the second-order study on the grounds that they did not meet the criteria for significant factors and matters of theoretical interest had been noted in Q-study A1. Thus 16 Q-sorts were entered (five factors from Q-studies A1 and A3 and six factors from Q-study A2). A four-factor solution was adopted, accounting for the highest percentage of study variance with valid factors (eigenvalue greater than one with at least two significant loadings) and allowing all Q-sorts to load significantly. For Q-study B, a six-factor solution was adopted as accounting for the largest amount of variance with clear factor structure.

Interpretation of the Factors

For each study a factor array is presented which indicates the weighted scores for each factor on every item. The factor arrays for the results that are presented for chapters 6 and 7 have been included in the Appendixes in the format illustrated in Table 4. This format was chosen so that the reader can refer to the factor array while reading the factor interpretations.

Table 4: *Structure of Tabular Presentation of Factor Arrays*

Statement	Factor 1	Factor 2	Factor 3
1.They are hidden away from the community.	0	0	1
2. Their disability is the fault of their mother because of something that she has done wrong.	-2	1	0
3. They are more likely to be poor than other people.	1	-3	+2
4. They have not had enough of the right chances to learn.	3	2	1

Note. The numbers in the factors columns represent the weighted average ranking score of loading participants.

For each Q-study, the statistically significant distinguishing and consensus statements are noted to review areas of commonality and difference. The statements themselves (not just the numbers of the statements) for each factor were placed into the response grid factor recreating an idealised Q-sort for that factor, as illustrated in Appendix D. For Q-studies A1, A2, A3 and A4, there were very few statistically significant distinguishing and consensus statements (possibly due to the limited rating scale of -3 to +3, as noted above). I therefore decided on an arbitrary criterion of two ranking points between the highest and lowest ranking given to a statement on a specific factor as reflecting a *degree* of consensus. In addition, I adopted the criterion of five points or more separating the highest and the lowest ranking score as a useful guide to factor interpretation, indicating a *degree* of disagreement. This is not of statistical significance but reflects rather the interpretation process where comparisons are made across factors in the process of constructing a narrative description of the factor (Stenner, et al., 2008). The significance of these disagreements will be highlighted in the factor summaries in chapter 6 and used to support factor interpretation. For Q-study B, there were sufficient statistically significant consensus and distinguishing statements to aid interpretation and this procedure was not deemed necessary.

While ranking scores are compared in factor interpretation, it must be noted that the rank given in one factor is not directly comparable with that given on another factor. A ranking of -1 might indicate a greater degree of disagreement for one factor than for another. This is because each factor is interpreted as a whole and the rank accorded to any one statement must be considered in the light of rankings given for other statements within that factor.

Each factor was then described by building a narrative account of the factor by:

1. Examining the items given the extreme scores (3, 2 and -3, -2 for Q studies A1, A2, A3 and A4 and 6, 5, 4 and-6, -5 and -4 for Q studies B1 and B2).
2. Noting the differences between factors in scores. For example, while a score of +1 might not be extreme, it is noteworthy where all the other factors have rated that item at-6.
3. Linking the comments of the participants to factors in order to describe the factor more clearly.

I looked for evidence in support of this interpretation in the comments made by participants. There were three sources of comments:

1. Comments on the items that they most strongly agreed and disagreed with.
2. Additional comments made on statements where participants felt that they would like to clarify their views.
3. Comments on their general understanding of intellectual disability and education of people with intellectual disability.

These comments were used to clarify the interpretation and to include participant voices in the researcher's narrative. The comments of the participants were, in addition, useful for illuminating apparent discrepancies within a factor. What the researcher might see as a discrepancy might in fact reveal a subtlety that is being expressed by the participants. For example, in one account of intellectually disabled people, the statement "*38. It does not matter what you call these people, intellectually disabled or mentally retarded, because the disability is still there.*" was rated very positively. While at first it would indicate that this account portrayed negative labeling as unimportant, the comments revealed that there was a great deal of concern about this practice but that one should attempt to ignore it. In this sense labelling does not matter because the individual should not allow himself or herself to be intimidated by this practice. These subtle distinctions are not readily observed from the factor analysis alone. Paying close attention to these subtleties allows the researcher to listen more carefully to the participants and to adopt the participant perspective even if it seems to be contradictory at first.

At some point in building up the narrative, I named each factor with great caution. Kitzinger (1999) notes that the labels that are used for factors are contestable. Following her caution, I have presented the full factor arrays and the sets of Q-sort items for each Q-study in the Appendixes. This permits scrutiny of the ways in which factors have been described here.

For both Q-sets, a set of thematic categories to organise the data was constructed, both for ease of presentation and analytical purposes. These categories are not identical with those that were used in the Q-set development process, nor with categorical distinctions that were made in chapters 3 and 4 regarding intellectual disability and educational practices. They are, however, informed by these categorical distinctions and reflect a reconstruction of themes within the particular context of this study. This accords with R. Stainton Rogers' (1995) view that a thematic analysis can be used as a tool for developing the Q-set but should not fix categories for analysis as this has the possible effect of fixing the participants' understanding *a priori.*

Notational Conventions

In factor description, certain notational conventions have been adopted. The Q-studies are labelled A1, A2, A3 and A4 for Q-set A. There is only one study of Q-set B. Each factor within the Q-study was labelled as well. Thus the factors in Q-study A1 are A1.1, A1.2, A1.2A, A1.3 and so forth. In Q-study A2, they are labelled A2.1, A2.2, A2.3 in similar fashion. While these factors are also given verbal names, they are often referred to in discussion by these shortened numerical forms.

Each statement in both of the Q-studies is numbered and the statements in the Q-sets can be found in the factor arrays, presented in the Appendixes. In discussion of factors, the statement number and the rank that it is allocated appear as a reference for any claims made about the relative significance of that statement for the factor. For example, a ranking of +6 on Statement 35 in Q-study B might be noted as important and would be referred to as (S35: +6). When participant comments relating to a specific statement are quoted to substantiate a claim made about a factor, this is noted in the following manner (S35: +6, P21). However, this does not mean that this participant necessarily gave the quoted ranking to the statement since the rating is drawn from a weighted average in the factor array. The participant serves as an advocate or spokesperson for the account identified by the factor, not as merely expressing his or her own idiosyncratic view. In some cases the participant's comment might not relate to a specific statement (such as when it is drawn from comments of most agree with and least agree with or a general understanding); in this case it is referenced with the participant number alone as in (Comment, P21).

Once the factor descriptions were derived from the data, a more in depth process of interpretation specifically aligned to the research questions was undertaken. In chapter 8, an analysis of the construction of the intellectually disabled subject in the light of the theoretical framework presented in chapter two and literature review undertaken in chapter 3 is presented. This aspect of the research moves away from the application of Q-methodology and seeks to identify the effects of the discourses identified through Q.

Research Methods to Identify the Effects of These Discourses

In addressing the third question, regarding the constructive effects of discourses of intellectual disability and associated educational practices, I focused on the relations between Q-study A and Q-study B. It is not possible to make a direct statistically significant comparison between the factors of Q-study A4 and Q-study B since they have different participants and Q-sets. I therefore made the connections at a conceptual level where there appears to be valid reason to associate two factors, one from Q-study A4 and one from Q-study B, on the grounds of conceptually similar understanding of intellectual disability. In this section, I relate the discourses arising from the current study to the literature and locate them in a social and historical milieu. This analysis is presented in chapter 8 as an interpretation of the findings.

Ethical Considerations

There has been much debate within the disability movement as to who should do research around disability issues (Duckett, 1998). The experiences of people with disabilities have understandably led to some suspicion on the part of disabled people for non-disabled researchers. This suspicion is exacerbated when the research ignores the experience and theorising of disabled people (Shakespeare & Watson, 1996).

One way of building trust is through transparency where the researcher is clear about his or her role, experiences and expectations (Scior, 2003). To this end I shall present a brief overview of my position and my reasons for undertaking this research. I have been a practitioner in the field of disability for the past 32 years, beginning with my qualification as a speech and hearing therapist in 1976. I became involved in the educational aspects of disability in my work in the rural areas of South Africa in the late 1980s through working on community based rehabilitation programmes that highlighted the lack of opportunity afforded young people with disabilities. My specific focus on *intellectual* disability arises from the birth of my son with Down Syndrome 15 years ago. I am a white middle class woman who has primarily worked in non-racially aligned or largely black, African contexts. While I remain sceptical about concepts of race and their continued deployment within the South African context, it would also be foolhardy to deny the impact of racial classification through apartheid policies on myself and in my relations with other cultural or racial groups. In my working life I have always been engaged in supporting non-governmental and voluntary associations for the support of disabled people, both in a paid and voluntary capacity. To describe my position with respect to the current research, I would say that I am widely known in the research community as an advocate of disability rights, most especially in terms of access to education in mainstream settings. My perspective is made clear within this research since I have followed R. Stainton Rogers (1995) by including my own views as a participant in the Q-sorting process. Unlike for any other participant I have identified my factor loadings and I can therefore be directly positioned with respect to the various accounts or discourses presented in this study. However, I have made every attempt to honour the views of all participants by presenting their views dispassionately and respectfully.

The Department of Psychology Research Projects Review Committee of Rhodes University gave the ethical clearance for the research. I am committed to ensuring that the results of the research will be freely disseminated through the following processes:

1. Inviting all participants to a meeting to give feedback on the research and its possible relevance to them. This dissemination will include consideration of ways in which the results can be made accessible to intellectually disabled participants.
2. Presenting aspects of the research at academic conferences. To date I have presented two papers on the topic (McKenzie, 2005, 2008).
3. Publication of results in academic journals. This will be done subsequent to the successful completion of this thesis.

According to Mouton (2005), research with human subjects needs to take into account the person's right to privacy, to anonymity and confidentiality, to full disclosure of the nature of the research in the form of informed consent, the right not to be harmed, and special rights for vulnerable subjects. I shall discuss each of these below.

Right to Privacy

Interviews were conducted in privacy except where the participant specifically requested the presence of a trusted person, which happened in only two cases of intellectually disabled people. Participants are anonymous in the research write-up as they are identified only as numbers.

Full Disclosure of the Nature of the Research

Each participant was given a letter outlining the nature of the research. This was both in a standard and easy to read format (see Appendixes E and F). Where participants were unable to read, the researcher read through the letter with them. They were given the opportunity to ask any questions at this point.

Informed Consent

After reading the information letter, participants were asked to sign a letter consenting to participate in the study, presented both the in easy to read and regular formats (see Appendixes G and H). Where consent was required from a guardian or an institution, this was obtained. Specifically consent was sought and gained from the Department of Education, management of the McClelland Centre for the Intellectually Impaired and REHAB. Each individual also gave his or her own consent. All other participants were given a letter of information and a consent form to sign agreeing to be part of the study.

The Right not to be Harmed

There was no indication that any harm to an individual could result from participation in this research. It required participation in a 30-60 minute interview with no further obligation, except that they might be asked to give consent for a further interview at a later date. The researcher did not take up this option and only one set of interviews took place for each participant. Given the attention paid to anonymity, confidentiality and privacy, they could not be penalised at a later stage for any comments they made.

Special Rights of a Vulnerable Group

Intellectually disabled people can rightly be termed a vulnerable group and thus I paid particular attention to possible concerns around their participation. I shall therefore discuss this in some detail below.

While it could be assumed that persons with intellectual disability might not have the legal capacity to give informed consent, this is not a simple matter. The matter hinges on

1. The capacity of the person to understand what the research is about
2. The likelihood of harm to the person concerned.
3. The autonomy of the individual to make their own decisions from a human rights perspective.
4. The role of the parent where the person is still dependent on the parents.

My reasoning on each one of these is presented below.

The capacity of the person to understand what the research is about.

I interviewed persons categorised as having an intellectual disability who have had experience of education specifically addressed toward intellectually disabled people and who gave some indication that they were able to understand the purpose of the research. A systematic strategy was adopted in order to present the information in an accessible format to the participants. This entailed an easy to read format, reading the information letter when participants were unable to read it themselves and clarifying their questions as well as using my judgement as to whether they needed further simplified information. Ultimately the decision as to whether they fully understood was a judgement call. I drew on my extensive experience in the field to make this judgement. In most cases there was every indication that they wanted to participate and appreciated the opportunity to make their views known. Some participants expressed anxiety about their capacity to complete the task and others were concerned as to whether they would need to be involved beyond the interview. I was able to reassure them on both counts. There was only one participant who wanted her mother to agree to her participation and to explain to her what was required. Once this was done she was willing to participate.

The likelihood of harm to the person concerned.

In my considered opinion, participation in the study posed very little risk of harm. The participants were required to rate statements according to whether they agree with them or not. There was no invasive procedure or highly sensitive information involved. Indeed, one of the advantages of Q-methodology is that it does not seek for personal or intimate information about any person's experiences or feelings (W. Stainton Rogers, personal communication, 12 August 2008). Procedures of confidentiality in the interview were strictly adhered to. Anonymity in this thesis is preserved since their names are not used and the discussion of responses is structured to ensure that anonymity is preserved. The information was processed according to acceptable academic standards and the outcome of the study is expected to make a positive contribution to the lives of intellectually disabled people. In one case a participant reported a history of sexual abuse. Noting my duty to report any form of abuse, I reported this to her mentor at school. She informed me that when the participant was at school, they had been made aware of these issues and had worked with the family to prevent further abuse. There was no prosecution but I was assured that she was no longer in danger from the abuser.

The autonomy of the individual to make their own decisions from a human rights perspective.

The current situation with regard to legal capacity of intellectually disabled people is not very clear due to numerous changes in the law. The submission by Disabled Children's Action Group (2004) on the Children's Bill emphasises the need for granting decision-making powers to disabled children while taking into account the developmental stage of the individual:

> There is a tendency for parents of children with disabilities and chronic illnesses to take decisions on behalf of their children. These children are rarely consulted or given opportunities to participate in decisions that affect their lives. Parents tend to feel pity and as a result over-protect their children, not transferring skills or equipping them to lead independent lives. There is a need to meaningfully involve the child in all decisions affecting their lives, taking into account their developmental stage (as opposed to chronological age). (Disabled Children's Action Group, 2004, p.15)

The view of the disabled child as unable to make decisions for themselves continues to be applied to the intellectually disabled adult. This view is challenged when they are given the opportunity to give informed consent.

Lack of mental capacity cannot be seen as an unproblematic concept according to the South African Law Reform Commission (SALC):

> It has been said that a legally and medically usable definition of capacity that is both sufficiently specific to avoid false positives and broad enough to avoid false negatives is probably impossible. Work done by law reform commissions in other jurisdictions reflects the difficulties in attempting to achieve a precise, easily measurable and easily applied legal definition of decisional incapacity. (South African Law Commission, 2003, p.46)

Capacity to make decisions is also not a blanket capacity that applies to every situation:

> In spite of difference of opinion on the suitability of specific standards of evaluation, it seems to have been uniformly accepted that capacity to make personal choices must be

> judged on a decision-specific basis as opposed to a global all-or-nothing basis. (SALC, 2003, p. 47)

In addition, there is no legislation that regulates the determination of incapacity but decisions are made through common law principles with the assumption that incapacity needs to be proved by the courts:

> The tests for legal capacity and the effects of incapacity of persons with mental deficiency are determined by common law principles as extended by the Courts and are not regulated by legislation. (SALC, 2003, p. 49)
>
> The present mechanisms to identify incapacity for legal purposes are based on the premise that a person is presumed to have the requisite capacity. A lack of capacity must be alleged and proved before a Court in order that it may decide the issue. The onus is upon the person alleging lack of capacity to prove this allegation. (SALC, 2003, p. 52)

Thus, there can be no automatic assumption of mental incapacity. In addition, there are sound reasons for obtaining informed consent from a human rights perspective where the individual is able to appreciate the nature and consequences of the act in question.

The role of the parent where the person is still dependent on the parents.

Whereas the intellectually disabled person might have the capacity to decide on their participation in research, there is little chance of their being entirely independent. In most cases they were partially or wholly dependent on their parents or guardian or an institution. It was considered a courtesy, and an acknowledgement of the significant role that the parents or guardian plays, to ensure that they are informed as to the purpose of the research and that they agree to their son/daughter/ward's participation in the research.

In consideration of all these aspects, I took the following approach with intellectually disabled participants.

1. The intellectually disabled participants were all recruited through reputable and trusted advocates, their schools, service providers and parents. I explained the purpose of the research to these agencies, all of whom gave their full support to their participation. Interviews were booked well in advance.
2. Intellectually disabled participants were informed of the purposes of the research through a verbal explanation accompanied by an easy to read document for those with adequate levels of literacy.

3. They were asked three questions to check their understanding of the purpose of the research. Where they were unable to respond to these questions correctly, the relevant information was given to them again. After this, all participants were able to answer the questions and were then asked to sign a consent form, either with their name or a cross if they were unable to write.

Context of the Study

This study was conducted in Buffalo City in the Eastern Cape province of South Africa. According to Stats SA, the Eastern Cape has the second highest poverty levels in the country with 47% of households below the poverty line. It also has the highest provincial unemployment rate at 55% in the age group of 15-64. Over one third of the population, 37% (more than 2 million people) are under the age of 15 and therefore of school going age. Twenty three percent of the population aged 20 years or older had no formal education according to the 2001 census (Statistics South Africa, 2003). Thus intellectually disabled children in the Eastern Cape are disadvantaged through poverty, unemployment of their parents, a huge pressure on the education system and, to some extent, parents or grandparents who have not had the benefit of formal education.

HIV/AIDS is the leading cause of death in the province. Mortality statistics indicated in 2000 that this disease accounts for 17% of male deaths and 23% of female deaths. Philpott (2004) notes that the urgency of the HIV/AIDS pandemic in the context of limited resources has the effect of placing disability as a low priority for service provision.

The study was conducted in Buffalo City, the new municipal structure that came into existence after the 2000 local government elections. It includes East London, King Williams Town and Bisho, and many surrounding smaller communities. There were about 880 000 people living in Buffalo City according to the Quality of Life survey conducted in 2001 (Morrow, 2002). Of these more than 80% are black African, about 10% are white, 6% are coloured and fewer than 2% are Asian. Almost one third of Buffalo City’s adults are unemployed with an average monthly income in 2001 of about R2 655 (USD265). There is a large disparity in income per household between racial groups (Morrow, 2002). It is in this setting that intellectual disability is problematised, largely around issues of exclusion – exclusion from education, exclusion from social interaction and exclusion from economic activity (Philpott, 2006).

In terms of provision for disabled children in the district, the implementation of progressive policy has been far from unproblematic. Philpott (2004) highlights the barriers that disabled children still face, in particular:

1. There is still a high level of exclusion from education and early childhood development (ECD) services.
2. There is some improvement for provision of health services within primary health care but access to rehabilitation services remains poor.
3. There is insufficient protection for children with disabilities from abuse within the family and the community.

This study focused on the education district of East London within the Buffalo City municipality. In this district, there are two schools (Khayalethu and Parkland) run by the Department of Education specifically for intellectually disabled children. There are several informal centres for disabled children including those with intellectual disability that are run by parents in the informal settlements and former townships in Buffalo City. There is also a more formal centre (Canaan Care Centre) for severely disabled children in the city centre. Other children are accommodated with difficulty in the mainstream and many are kept at home in the absence of any suitable provision for them.

In 2008, parents of disabled children sent a memorandum to the East London district manager for the Education Department outlining the following grievances:

1. Regular schools do not want to admit children with intellectual disability and if they do they are reluctant to promote them.
2. Special schools have long waiting lists and do not want to admit children with more severe or “difficult” disabilities. Some children wait so long for admission that they are eventually excluded on the grounds that they are overage for admission after 13 years old.
3. Teachers in regular schools must be well trained in working with learners who experience barriers to learning. They should be able to draw up, implement and monitor individual support plans for such learners.
4. There should be awareness about disability in schools and in the community to combat the negative attitudes.
5. Schools should be physically accessible to learners who make use of wheelchairs.

6. Parents should start with early intervention so that when the child comes to school he or she is well-prepared.
7. There should be health services in schools to assist disabled children. (REHAB & DSAA, 2008)

These concerns reflect a situation where inclusion in the mainstream is both difficult and perceived as not necessarily helpful if the teachers are not trained. The alternative to mainstream is special schools, which are also difficult to get into and favour the less severely disabled child. Barring these two options, the child faces exclusion from schooling altogether, which is not an uncommon occurrence in Buffalo City (McKenzie, 2007).

These parental concerns were expressed at a time when the Department of Education, through the District Based Support Team (DBST), is training schools in processes of screening, identification, assessment and support. As part of this process the DBST has taken over the control of admission to special schools from the special schools themselves so that there is a centralised decision -making process.

Conclusion

In this chapter I have presented my rationale for choosing Q-methodology as my research method. I have indicated that the method is suited to the exploration of diverse accounts of any topic and I have applied it to intellectual disability and the education of those who are labelled as such. I have argued for a discourse-based use of Q-methodology, drawing on the DA school of Q-method. I have outlined the specific method used in this study, including the research questions, research method and ethical considerations. In so doing I have given the background for the presentation of findings in chapters 6 and 7.

CHAPTER 6: DISCOURSES OF REPRESENTATION OF INTELLECTUAL DISABILITY

> Basically intellectual disability is like, nothing to do with speech, but being sidelined as something of an outcast and not being involved in anything. If people are having a conversation, you try to contribute but you end up being turned away like what you say doesn't matter to them. (P17: Q-study A1)
>
> They [intellectually disabled children] are children that need love, care and development in areas of need. They are disadvantaged more than being disabled. Generally they are also human beings that have rights to be considered. Patience, love and care can bring good results. (P18: Q-study A2)
>
> Intellectual disability is when someone is not reasoning normally, cannot make sound decisions due to brain damage. It can be described as malfunctioning of the brain affecting his/her thinking skills and also it can be caused by slow development of the brain during pregnancy. (P30: Q-study, A3)

The above quotes from participants in the current study illustrate that the category of intellectual disability is by no means a simple unproblematic one that is generally agreed upon. In recognition of this multiplicity of meanings I posed the question:

1. What discourses are deployed in the representation of those identified as intellectually disabled in Buffalo City, South Africa?

In this chapter I address this research question, through the findings from Q-studies A1, A2, A3 and A4, all of which are derived from Q-sorting processes of Q-set A. These findings identify accounts of representation of intellectually disabled people through the factor analysis from three different groups of people in four Q-studies. These groups have been noted in chapter 5 and are repeated here:

1. Q-study A1: Adults with intellectual disability.
2. Q-study A2: Parents of people with intellectual disability.
3. Q-study A3: Professionals who work with people with intellectual disability.

As noted in chapter 5, the factor descriptions from the Q-studies A1, A2 and A3 will be referred to as "accounts" rather than "discourses" as they are considered to represent variable accounts. The regularity of discourse is sought in the fourth Q-study, A4, as a second-order study. Subsequently, in chapter 7, I shall examine discourses of educational practice for those categorised as intellectually disabled.

Results

The reporting of factors arising from Q-studies A1, A2 and A3 is kept to a brief description, with the focus on the identification of their distinguishing features and areas of consensus. Each factor is named with a descriptive phrase or sentence that highlights the outstanding features of the factor. The tables referring to factor loading and factor arrays are presented in the appendixes since the reader may want to refer to them repeatedly and this makes for ease of reading. Finally, the factor descriptions for Q-study A4 are presented and more generalised discourses of intellectual disability are identified.

For each Q-study a summary table is presented. The summaries of factor descriptions are presented in thematic categories for conceptual clarity and consistency. These themes are not separated out as analytical elements but rather they form part of the fabric of any one account as they weave in and out with each other in ways that construct meaning differently as a synthetic whole for each factor. These themes are presented below:

Organic impairment – this refers to the notion of intellectual disability as an organic defect of the brain that imposes limits on intellectual functioning and cannot be cured.

Difference **–** in this category aspects that relate to the existence of difference and the significance of difference from the norm are noted.

Spirituality – this is a broad category that covers the notions of disability as a gift from God that can be either a blessing or a trial as well as the social inclusion of disabled children within religious spheres.

Competence **–** within this category, I have grouped concerns with being able to do things in the world, whether it be looking after money or taking responsibility.

Social inclusion – this category relates to the extent that the disabled person is, or should be, included in every day community activities.

Autonomy – this category relates to the degree to which the disabled person is, or should be, able to make decisions for themselves.

Family – this encompasses family relations and their importance in the lives of disabled people.

As an aid to factor descriptions, the comments made by participants loading onto a factor are used to enhance and support the interpretation of that factor. The sources of these comments are:

1. Responses to the question: “What is your general understanding of intellectual disability?”
2. Explanations of their choices of the statements that they most agreed with and least agreed with.

Q-study A1: Intellectually Disabled Adults

The eigenvalues and percentage of variance accounted for by each factor is given in Table 5 below. The six-factor solution accounts for 48% of the variance with 19 of the 22 participants loading significantly at $p < 0.01$ onto a factor.

Table 5: *Variance Accounted for by Factors and Factor Loading of Participants in Q-Study A1*

Factors	1 Eigens	% variance accounted for by factor	Number of Q sorts loading onto factor at significance level 0.41 and participant numbers of loading participants in brackets
A1.1	2.32	11%	5 (3, 6, 14,16,20)
A1.2	1.06	5%	2 (12, 22)
A1.3	1.43	7%	2 (11, 18)
A1.4	1.22	6%	2 (2, 4)
A1.5	2.60	12%	5 (1,9,15,17,19)
A1.6	1.68	8%	3 (7,10, 13)
Totals	10.31	49%	19

I have named the factors as follows, according to the way the intellectually disabled person is viewed:

A1.1: A competent person.
A1.2: A person dependent on their family.
A1.2A: A vulnerable person.
A1.3: A person requiring special care and love.
A1.4: An (ir)responsible person.
A1.5: A person discriminated against.
A1.6: A stereotyped person.

The factor loading for each participant is indicated in Table 1 in Appendix I for easy reference. The factor array for Q-study A1 is presented as Table 2 in Appendix I. This factor array does not present with any statistically significant consensus statements. There is one statement that distinguishes Factor A1.2 from all the others, noted in Table 6 below.

Table 6: *Distinguishing Statement for Factor A1.2*

Statement	A1.1	A1.2	A1.2A	A1.3	A1.4	A1.5	A1.6
20. They are always made welcome in church and at religious places.	1	-3	3	2	2	3	1

This statement is rated at -3 compared to all positive ratings on the other factors. This contrasts with the overall positive rating of church involvement evident in the other factors. In the interpretation of Factor A1.2 below, it will be seen that the mediation of the family for social inclusion is valued much more highly than community mediation.

Using the criterion of two ranking point's difference between statements, as discussed in chapter 5, the following statements represent a degree of consensus across the factors. The ranking of Factor A1.2A (which is the *opposite* of that presented in the factor array above) is presented as a separate factor in Table 7 and subsequent tables below:

Table 7: *Statements that Reflect Substantial Agreement Across Factors for Q-Study A1*

Statement	*A1.1*	*A1.2*	*A1.2A*	*A1.3*	*A1.4*	*A1.5*	*A1.6*
17. They are very likely to be abused or treated badly.	-1	0	0	-1	-2	-1	-2
34. They can be thought of as children in many ways.	0	1	-1	1	0	-1	1
36. They are the same as other people in the way they act.	1	0	0	0	2	0	0

These statements reflect a mild rejection of the likelihood of abuse and a neutral view on whether intellectually disabled people can be thought of as children. There is a neutral to mild agreement that intellectually disabled people are the same as others in the way that they act.

Those statements that indicate a degree of disagreement with five or more ranking points separating them, as discussed in chapter 5, are presented in Table 8. Since Factor A1.2 is bipolar, each ranking statement is the opposite of the other and by the criterion of five ranking points difference between the highest and lowest ranking, all of the most positive and most negative rankings of A1.2 will indicate disagreement[2].

Table 8: *Statements that Reflect Substantial Disagreement Across Factors for Q-Study A1*

Statement	*A1.1*	*A1.2*	*A1.2A*	*A1.3*	*A1.4*	*A1.5*	*A1.6*
8. They often find it hard to behave or act in the right way.	-1	3	-3	0	-1	-1	1
10. They do not know how to stand up for their rights – things that all human beings should be allowed to do or have.	-3	-3	3	-1	0	-2	0
12. They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	-2	2	-2	3	0	3	1
16. They are scared of failing in learning.	-1	-3	3	0	1	-3	0
19. When parents and teachers plan for their future, they do not include the disabled persons dreams or wishes.	-3	-1	1	-2	-2	-1	2
22. They should be brought up within their families no matter what special needs they might have.	2	3	-3	3	2	1	0
23. They will always need a lot of help from their families.	0	3	-3	2	3	2	1
24. They bring something into the family because they can get a disability grant.	1	3	-3	-1	3	-1	-2
27. They look the same as other people.	2	1	-1	-3	-1	0	0
28. They are a gift from God.	3	-2	2	3	0	2	3
29. Their parents stop them from doing things because they are worried about what might happen to them.	2	-3	3	0	-1	-1	-1
30. Other people, like parents and doctors should not decide what makes their life happy and worthwhile.	-2	-2	2	-3	-3	0	-1
32. They treat other people with respect.	3	-1	1	2	-2	1	1
35. They can learn to do most things for themselves with time and patience.	0	-2	2	0	3	1	3

Note. The shaded cells represent the highest and the lowest rankings of the statement.

This table will be referred to in the findings below in support of factor interpretations. I shall now examine each of the factors below and give a narrative account of the emerging pattern.

Factor A1.1: A Competent Person

Factor outline.

Factor A1.1 explains 11% of the study variance and has five significantly loading participants and an eigenvalue of 2.32. These participants reflect a range of demographic

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[2] In terms of the narrative account of the factors the bipolar factors, A1.2 and A1.2A are considered independently as separate factors. However, PCQ for Windows analyses it as one factor with positive and negative loadings on the factor. This means that only one pole of the bipolar factor (A1.2) is analysed for statistically significant distinguishing statements. If factor A1.2A were included in the analysis, the chances of more statistically significant distinguishing statements occurring is high since between these two factors alone there is a high degree of differentiation since they are opposites.

variables since they are from all race groups across a range of ages from 19 through to 60 years of age, although four are under the age of 34. Three of them are employed in the open labour market and the other two are in sheltered employment. Their general understanding of intellectual disability, reflected by participant comments, indicates a fairly non-specific concept of experiencing difficulties in every day life that do not necessarily relate to intellectual ability.

Factor description.

For this factor, an intellectually disabled person is competent to meet the challenges of social inclusion in normal life. Intellectual disability is a part of life that poses a challenge but does not prevent a person from living a full life: *"I have brain damage but just because I have this it does not bother me because I can still have a normal life. I can eat, I can walk, I can talk"* (S5: -1, P14 comment[3]). The distinctive statements (see Table 8) for this factor are S10: -3, S12: -2, S19: -3, S27: +2, S28: +3, S32: +3. The view that this shapes is that intellectually disabled people can stand up for their rights and they do not require therapeutic help in order to live a normal life. The involvement of parents is seen to support the intellectually disabled person who is an asset to society as they are a gift from God, and not substantially different from others. They treat others with respect.

Competence is highlighted in this account, since intellectually disabled people are able to enjoy music and dance (S31: +3), they are seen as being able to engage in relationships (S11: +1) and to earn (S39: +1) and manage (S40: -2) their own money. This competence extends to being able to stand up for their rights (S10: -3). Intellectually disabled people have a desire to learn both academic skills, such as reading and writing (S15: +3) as well as life skills (S13: +2). Within this factor, there is a strong rejection of the notion that there can be a limit to learning: "*That's where the problem comes. I was in my school for many years but then it gets to the point that you have to leave. If you could carry on with school, then you would learn more"* (S14: -3, P14 comment). Intellectually disabled people are not hidden from the community (S1: -2). Social inclusion and competence go hand-in-hand since

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[3] The notational conventions are described in Chapter 5. The first number (prefixed with 'S' indicates the number of the statement and the second number is the score given to this statement in the factor array. The participant number is given last, prefixed with 'P'.

it is through social engagement that competence is enhanced. Overprotection is unwarranted since they are able to stand up for their rights themselves (S10: -3).

The family is of central importance in that it is important for parents to help with making decisions (S19: -3) and intellectually disabled people should always be within the family (S22: +2), but families can be overprotective (S29: +2). This factor is similar to Factor A1.5 but differs in a greater emphasis on the unimportance of difference and the slightly greater degree of autonomy and independence from the family.

Factor A1.2 and A1.2A

Factor A1.2 as presented in the results section is a bipolar factor. This means that the ranking of a statement by participants that load positively onto the factor are mirror images of the rankings of the negatively loading participants. Each represents a different position that is in an oppositional relation to the other. Since the account that emerges from each end of the opposition is likely to be very different to the other, the bipolar factor must be interpreted as two separate factors (Watts & Stenner, 2005).

Factor outline.

Factors A1.2 and A1.2A together explain 5% of the study variance and have two significantly loading participants, both female; P12 is white (30 years old) and P22 is “coloured” (22 years old). P12 loads positively onto the factor (A1.2) at 0.61. P22 has a negative factor load of -0.59 (A1.2A). The situations of these two individuals are disparate. P12 is in residential care and works in the sheltered workshop. She has a very close relationship with her middle class family, whom she visits on weekends. P22 works in the open labour market and lives with her mother in a low-income household where her income makes a sizable contribution to the family. P22 on Factor A1.2A describes herself as having an intellectual disability that means that she cannot read and write and she describes intellectual disability in general: *“It is when you struggle to do something and it takes longer for you to do it than the other children who are quick. That is the only difference”* (Comment, P22). Participant 12, on the other hand, notes that she has a disability because she gets a disability grant.

Factor A1.2: A Person Dependent on their Family

In this account, the intellectually disabled person is incompetent and their family mediates their social inclusion. The roots of difference lie in an organic impairment that prevents normal engagement with the world (S5: +2). This deficit causes the intellectually disabled person to be incompetent in running their own lives and therefore dependent on the family to make decisions for them. Individual autonomy and competence is less valued than the protection of the family. The distinctive statements for this account (see Table 8) indicate that intellectually disabled people can stand up for their rights (S10: -3) and are not afraid of failure in learning (S16: -3) as they are protected within the family (S29: -3) that will always be needed to give them support (S23: +3). They will always belong within the family (S22: +3) and can contribute by means of their disability grant (S24: +3). An intellectually disabled person finds it hard to act in the right way (S8: +3), and is not considered to be a gift from God (S28: -2). He or she has limited potential to learn (S35: -2). These limitations are more important than strengths (S37: -2). Since the intellectually disabled person is always treated well and fairly (S21: +2), competence is of little concern (S25: -2). Factor A1.2 expresses a distance from difficulties experienced by disabled adults and credits little competence: *"They do the wrong thing, not the right thing"* (S10: -3, P12). There is a lack of confidence and self-worth evident in this factor as they often find it hard to behave in the right way (S8: +3) and require therapeutic intervention to live a normal life (S12: +2). They are seen to be incompetent in that they are not able to do more than people think they can (S25: -2) and they are only able to work where they are kept safe (S33: +2). In this account support is solely from the family and they are not necessarily made welcome outside of this charmed circle (S20: -3). They are not even made welcome in the church, a distinguishing statement for this factor, which is rated at -3 (see Table 6).

Factor A1.2A: A Vulnerable Person

The factor scores quoted in this summary are the *opposite* of those listed in the factor array in Table 2 in Appendix I since this factor is the polar opposite of the Factor A1.2. An intellectually disabled person is vulnerable to abuse where family support is absent. The distinguishing statements of this account give an overall picture that acknowledges the difficulties encountered in everyday life (S16: +3) but these difficulties do not, *per se*, prevent an intellectually disabled person from living a normal life (S12: -2). The position of the individual with respect to the family and the community is more important. This factor illustrates a struggle with being independent in the absence of family support. Their parents tend to limit their choices (S29: +3) and others make decisions for them (S30: +2).

The factor expresses a high degree of vulnerability and fear of exploitation of intellectually disabled people in that they do not know how to stand up for their rights (S10: +3): *“Sometimes it is difficult to talk when something is wrong or happening to you. Then you are scared to talk”* (S10: +3, P22). Church and religion is very important for this account as it represents a site of acceptance and acknowledgement of worth for intellectually disabled people: *“In church they don't worry, they welcome everybody. It is God's place. They are friendly and you can make friends there. They mustn't judge themselves because it is just a small problem that they have”* (S28: +2, P22).

There is confidence in the ability to live a normal life (S5: -2) in spite of organic impairment but it requires a lot of effort: *“You can't help it when you forget things but you can live a normal life if you try”* (S5: -2, P22). There is evidence of a painful degree of awareness of the difficulties experienced: *“You try to pretend but its very hard. Sometimes you do wrong things and you have to fit in with [be responsible for] those things”* (S8: -3, P22) and *“You try and try and you can’t really do it – maybe you come right but then you forget”* (S4: -1, P22). The overall impression here is that the acquisition of skills is not enough if one has to live in a society where the intellectually disabled person does not know how to stand up for their rights (S10: +3) and where they are not always treated fairly (S21: -2). An additional burden is that of teasing: *“People call you names all the time. They say you go to a mad school”* (S38: +1, P22). If there were a more positive view of intellectual disability their participation in society would be greater (S37: +2).

There is a distance from the family. Contribution to the family through a disability grant is linked with exploitation: *“The child can't help it. The child was born like that. The child should get it (the disability grant) but sometimes the mother takes it and she drinks”* (S24: -3, P22) and abuse is indicated: *“It is not nice being beaten. I was abused by my oupa [grandfather]”* (S21: -2, P22).

Factor A1.3: A Person Requiring Special Care and Love

Factor outline.

Factor A1.3 explains 7% of the study variance, with an eigenvalue of 1.43. It has two significantly loading participants, one male (P11) aged 32 and one female (P18) aged 23. P11 is resident in the hostel and P18 lives in a flat with her boyfriend and works as a machine operator. She identifies as having a hearing disability but does not mention intellectual disability.

Factor description.

Regardless of difference, an intellectually disabled person should be socially included by families and communities in the light of common humanity and religious values. The distinguishing statements, as indicated in Table 8, emphasise the importance of therapeutic intervention (S12: +3) for living a normal life. The family is central (S22: +3) and offers the right kind of support in decision- making (S30: -3) in the presence of difficulties associated with intellectual disability:*"Because they have got problems so they need the help of the family"* (S22: +3, P18).

This account is similar to that of Factor A1.5 but differs in an acceptance of the existence of difference as something that is unproblematic:*"People can't look the same, do the same things"* (S27: -3, P18). They must not try to be like other people (S6: -3) because they are fine as they are: "*They are nice people"* (S6: -3, P18). Difference is given a positive value by calling on family values and a philosophy of sharing and helping each other: *"People should not hide themselves away. They should talk with one another*" (S1: -2, P18) and: *"People must enjoy one another and appreciate one another"* (S31: +3, P18). The value of difference is couched in spiritual terms: "*We can't be the same we are each different. God made us different"* (S27: -3, P11) and: *"I believe in God. He made us and God is love. He made us all different"* (S28: +3, P11).

There is also less emphasis on autonomy as family and community are generally seen to be supportive. This account is similar in some respects to that given in Factor A1.2 in the strong role of the family in mediating social inclusion. However, in A1.3 difference is given a positive value as opposed to the negative light cast on difference in Factor A1 .2.

Factor A1.4: An (Ir)Responsible Person

Factor outline.

Two participants load onto this factor, P2 who is white, male and 29 years old and P4 who is white, female and 40 years old. Both are residents in the hostel and both were able to read the statements for themselves. Their understanding of intellectual disability is expressed in such a way as to mark themselves off from others: "*Some people don't learn quickly enough.*

They take a long time to learn. They have to think before they write or say something. I am quick to pick things up. I can learn all the songs for the choir even the difficult ones" (Comment, P4).

Factor description.

In this account a distinction is made between more competent and less competent intellectually disabled people. A double perspective of intellectual disability is indicated with a positive image of a keen, motivated learner who takes responsibility for their own learning and an irresponsible person who exhibits anti-social behaviour. The distinguishing statements from Table 8 figure intellectually disabled people as not treating other people with respect (S32: -2) and as being incapable of having a long-term relationship (S11: -2). Intellectual disability is associated with irresponsible behaviour*: "Some of them have got money and they save it up and then go to the office and keep it there. They use it all up in one day on sweets. But I am good at saving up"* (S40: +1, P2). Parents and doctors should decide for them (S30: -3), as they are not able to take responsibility (S18: -2): *"If some of them can't think, the doctors and nurses must decide for them. Others who can decide, then they must think for themselves"* (S30: -3, P2). They are not able to manage their money (S40: +1) and they can never have their own home (S9: +1).

In contrast to the irresponsible person, there is a responsible intellectually disabled person who is willing to learn (S15: +3) and can be successful with the right kind of teaching (S35: +3). This group wants to learn how to read and write (S15: +3) and can learn to do most things for themselves (S35: +3). There are two classes of intellectually disabled people, those who take responsibility and those who do not. They can become competent if they try hard enough: *"If they take time and try hard then they can do something about themselves"* (S35: +3, P4) and learning is something that one can choose to do: *"They can learn if they want to. They must choose to learn"* (S16: +1, P2).

This factor emphasises competence over social inclusion, suggesting that competence is a precursor to inclusion and something that one earns through being responsible about learning. The potential for leading a normal life is not necessarily determined by organic impairment and professional treatment (S5: -1, S12: 0) but rather by the extent to which the individual applies him or herself to self-improvement.

Factor A1.5: A Person Discriminated Against

Factor outline.

Factor A1.5 accounts for 12% of the variation and has an eigenvalue of 2.62. There are five participants who load onto this factor and they represent a diverse group, across dimensions of race, gender, age and disability. P1 is a white male of 35 years with a good literacy level. He attends the workshop for the intellectually disabled on a daily basis but lives at home with his family. He has a physical disability and identifies himself as physically, rather than intellectually, disabled. P9 is a white female, 46 years old, , also with good literacy levels, who lives in the hostel. She states that she knows she has a disability because she gets a disability grant. P15 is a black male, 21 years old who lives with his family and is not working. He is unable to read and does not identify himself as having a disability. P17 is a black male, 23 years old, who stays at home with his family and attends the workshop on a daily basis. He has a physical disability and excellent literacy and language skills. He identifies himself as physically disabled. P19 is a 'coloured' male, 19 years old, who works in the open labour market and lives by himself in rented accommodation. He states that he has a disability in that he cannot spell or read very much.

Their understanding of intellectual disability is in relation to what is expected as the norm, either in terms of learning or social inclusion. The problem does not reside in the person but in what is expected of them and their failure to meet the requirements of being included: *"Basically intellectual disability is like, nothing to do with speech, but being sidelined as something of an outcast and not being involved in anything. If people are having a conversation, you try to contribute but you end up being turned away like what you say doesn't matter to them"* (Comment, P17).

Factor description.

This account places an emphasis on the equivalence of intellectual disability with other sorts of problems that people might have. As such it is part of the range of human adversity that might affect anyone. It questions why intellectual disability should be singled out for exclusion given that everybody has problems and everybody needs support: *"Other people must be the same as others. They might have some difficulties but not a disability. They mustn't think that they are better than the other person because they have also got problems.*

I am not the only 'bad luck' person with her own difficult problems. They must think of themselves before judging other people" (S37: -2, P9). Thus, they are treated unfairly and experience discrimination because the type of difficulty that they have is stigmatised.

The distinguishing statements of this account (see Table 8) indicate that much support is needed to live a normal life (S12: +3) and that intellectually disabled people want to learn without fear of failure (S16: -3). With this support, he or she can do whatever anyone else can do. They can manage their own money (S40: -3), and have their own home (S9: -3). They are able to stand up for their rights (S10: -2) and pose no special problem for parents (S7: -2). They also want to learn how to read and write (S15: +3) and feel confident that they can earn money to live on (S39: +3). Just as "normal" people can experience the problems that intellectually disabled people experience, so it works the other way around. Intellectually disabled people also have problems not associated with that label: *"They should be taught about relationships and sex because they are mature enough to know about their own bodies. They might get information from the wrong sources. They must also learn about STD's (sexually transmitted diseases) and teenage pregnancies and the dangers"* (S13: +1, P17).

This account is similar to A1.1 in its assumption of competence but differs in its recognition of the need for support from professionals and the family and the strong feeling of being unfairly treated. This is framed within the context of everybody needing support of some kind.

Factor A1.6: A Stereotyped Person

Factor outline.

This factor accounts for 8% of the variance and has an eigenvalue of 1.68. There are three participants loading onto this factor. Participant 7 is a white male, 24 years old who works on the open labour market as a shelf packer and lives at home with his family. He is not able to read, which is a source of great distress to him. He identifies himself as having a disability that makes reading and writing hard for him. Participant 13 is a 33 year-old white woman, who does not work and lives at home with her family. She was not able to read the statements. She identifies herself as having an intellectual disability. Participant 10 is white male, 36 years old, with excellent literacy skills. He writes stories in his spare time. He lives at home and attends the workshop for the intellectually disabled every day. He states that he has a disability that relates to his coordination but feels that this is improving, as he gets older. Participants loading onto this factor identify intellectual disability as a specific learning problem that is located within the individual.

Factor description.

This factor is concerned with the way in which stereotypical views of intellectual disability result in low expectations. The assumption of incompetence by society at large limits the opportunities that intellectually disabled people are given. Competence is very important and is something that the individual must strive for and they have the right to appropriate support and education. The distinguishing statements for this account (see Table 8) indicate that parents do not always take into account the disabled person's wishes (S19: +2). The understanding of being a gift from God (S28: +3) establishes the rights of intellectually disabled people and makes external differences unimportant: *"This is the most important to me. To Jesus we are all the same because he looks inside. We are all different but he made us all"* (S28: +3, P10).

Competence is highlighted in that they can learn to do most things if taught in the proper manner (S35: +3). The intellectually disabled person is motivated to learn but does not have enough of the right chances to learn: *"I didn't have the opportunity to learn. The years were wasted. We had flash cards but we did not have books until my last few years at school. I am willing to learn"*(S4: +3, P7).

Their potential is not acknowledged sufficiently since they can do more than people think if given the opportunity and the patience required: *"Cause I like that. I like patience. I am helpful. I make my room neat"* (S35: +3, P13) and: *"I can go onto the computer and print. I can do it by the place on the screen. People out there can give us a chance"* (S25: +2, P7). Society should be more accommodating by looking for strengths and having high expectations rather than focusing on difficulties all the time (S37: +2).

This account calls for the larger community to know intellectually disabled people better and become more accepting and tolerant: *"Those words, intellectual disability and intellectual* *impairment don't sound too bad. Some people don't come here. These people might call the people here mentally retarded. They don't take the time to know the person. It does matter. They used to call them mentally retarded but now I hear intellectual impairment a lot. Sometimes people don't know what to say. Sometimes we get a lot of support here at the centre but there are people who hear of McClelland and they don't know how to react. A lot of teenagers seem to feel awkward"* (S38: -2, P10).

This account is similar to A1.5 in that both recognise unfair treatment of intellectually disabled people. The difference lies in the effect of this discrimination. For A1.5 it leads to exclusion from social activity whereas for A1.6 it restricts work and employment opportunities.

Summary of Q-study A1

A summary of Q-study A1 is presented in Table 9 along the thematic dimensions noted above. The most important aspects of Q-study A1 are the family and issues around competence and social inclusion. The organic impairment is taken -for -granted as something that exists in some cases, but it is not recognised as important in others. Intellectual disability is a relational concept that comes into being in interaction, rather than a fixed property of the individual.

Table 9: *Summary of Factors for Q-study A1*

	A1.1: A competent person.	A1.2: A person dependent on their family.	A1.2A: A vulnerable person.	A1.3 :A person requiring special care and love.	A1.4: An (ir)responsible person.	A1.5: A person discriminated against.	A1.6: A stereotyped person.
Difference	Same as others.	Very different to others.	Different because of social exclusion.	Different but accepted as such.	Some are more different than others.	Difference is stigmatised, leading to discrimination.	Difference leads to stereotyping at a physical level but equal in the eyes of God.
Spirituality	Not important.	Not important.	Important site of acceptance.	Important to understanding of difference.	Not important.	Not essential.	Bolsters claims to fair treatment.
Competence	Competent to achieve most things.	Incompetent .	Can be achieved with difficulty, but not as important as social inclusion.	Not very important.	Something to be worked for as a moral responsibility.	Everybody needs support but people with ID need support in their competence.	Very important needs all the support and opportunity to achieve this.
Social inclusion	Very important.	Minimal – through family.	Not easy to achieve – unfair treatment and abuse.	To be found within church and family.	Depends on the level of competence.	Must be included within the normal range of diversity.	Stereotypes restrict inclusion.
Autonomy	Important to make own decisions with support.	Family must decide.	Must be autonomous but still vulnerable.	Family and community will make the right decisions.	Depends on the level of competence.	Can be autonomous.	Very important.
Family	Can be overprotective but is supportive.	Offers protection and support.	At best, family is absent and at worst, abusive.	Loving and supportive.	Supportive and acts in person's best interest.	Families support as they do all their members.	Supportive but do not always listen to the ID person.

Q-study A2: Parents

The data for the 31 parent participants were analysed as for Q-study A1. The eigenvalues and percentage of variance accounted for by each factor is given in Table 10 below. The six-factor solution accounts for 54% of the variance with 28 of the 31 participants loading significantly at $p < 0.01$ onto a factor.

Table 10: *Variance Accounted for by Factors and Factor Loading of Participants n Q-Study A2*

Factors	1 Eigens	% variance accounted for by factor	Number of Q sorts loading onto factor at significance level 0.41 and participant numbers of loading participants in brackets
A2.1	4.20	14%	5 (1, 2, 11, 14, 30)
A2.2	1.80	6%	4 (5, 19, 26, 28)
A2.3	3.00	10%	6 (7, 12, 20, 22, 23, 29)
A2.4	1.31	4%	2 (13, 18)
A2.5	1.50	5%	2 (17, 31)
A2.6	4.79	15%	9 (3, 4, 6, 8, 10, 15, 21, 25, 27)
Totals	10.31	54%	28

I have named the factors according to the understanding of the intellectually disabled person as follows:

A2.1: A citizen with rights.
A2.2: An innocent and vulnerable child of God.
A2.3: A difficult challenge to their family.
A2.4: A person with special needs.
A2.5: A person to be understood by the community.
A2.6: A blessing and a gift from God.

The factor loading for each participant is presented in Table 3 in Appendix I for ease of reference. The factor array was generated by the procedure as described in chapter 5 and is presented in Table 4 in Appendix I. There are two statistically significant consensus statements for Q-study A2, noted in Table 11.

Table 11: *Statistically Significant Consensus Statements for Q-Study A2*

Statement	*A2.1*	*A2.2*	*A2.3*	*A2.4*	*A2.5*	*A2.6*
15. They want to learn how to read and write.	1	2	1	2	2	2
25. They can do more than many people think they can.	2	1	1	2	1	2

Both of these statements reflect a moderate to strong belief in the capability and desire to learn of the intellectually disabled person. There were no statements that distinguished between the factors at a statistically significant level.

As for Q-study A1, I noted statements that showed a considerable degree of consensus with a criterion of not more than two points on the rating scale between the highest scoring and the lowest scoring statements. These statements are indicated in Table 12 below.

Table 12: *Statements that Reflect Substantial Agreement Across Factors for Q-Study A2*

Statement	*A2.1*	*A2.2*	*A2.3*	*A2.4*	*A2.5*	*A2.6*
2. Their disability is the fault of the mother because of something she has done wrong.	-3	-2	-3	-3	-1	-3
9. They can never have their own home.	-2	-2	-2	-1	-2	0
32. They treat other people with respect.	0	2	0	1	0	1

These statements reflect a rejection of blaming the mother and an agreement that intellectually disabled people can have their own home. A positive dimension of intellectual disability is that they treat others with respect.

As for Q-study A1, I adopted the criterion of five points or more separating the highest and the lowest ranking score. These statements reflect a level of disagreement between the factors and are shown in Table 13.

Table 13: *Statements that Reflect a Degree of Disagreement Across Factors for Q-Study A2*

Statement	*A2.1*	*A2.2*	*A2.3*	*A2.4*	*A2.5*	*A2.6*
5. Brain damage that makes learning difficult stops them from leading a normal life.	-2	0	2	-3	0	0
7. It is very difficult for parents to bring up people like this.	-1	0	3	0	-2	-2
11. They can have a long term relationship or get married.	2	-3	-2	0	1	-1
12. They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	-2	1	3	3	1	2
19. When teachers and parents plan for their future they do not include the disabled person's dreams and wishes.	1	-3	-2	2	-3	-1
22. They should be brought up within their families no matter what special needs they might have.	3	-1	-1	-2	1	1
27. They look the same as other people.	0	0	-1	-2	3	-3
34. They can be thought of as children in many ways.	-3	-1	0	-1	3	1
36. They are the same as other people in the way they act.	0	-1	-3	-2	2	-1
38. It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	0	2	3	-2	-2
39. They can earn money to live on.	0	0	0	0	3	-2

*Note***.** The shaded cells represent the highest and the lowest ranking of the statement.

As with Q-study A1, these relative disagreements between factors will be used to support factor interpretation below. The descriptions below are narrative accounts of the patterns evident in each factor.

Factor A2.1: A Citizen with Rights

Factor outline.

Factor A2.1 explains 14% of the study variance and has five significantly loading participants and an eigenvalue of 4.20. My own sorts are loaded onto this factor as Participant 2 and Participant 30, as I completed the Q sort twice (see chapter 5), reflecting a high loading that remained relatively constant from the beginning to the end of the research (0.92 as P2 and 0.88 as P30). I am a white woman, self-employed with a child[4] of 15 years. I did not include my comments in the Q sort as I felt that my views would be adequately represented since I have the voice of the researcher. P1 is a white man, 52 years old, parent of a child of 15 and self-employed. P11 is a white woman, 40 years old with two children with disabilities, one nine and the other three. She is a health professional. P14 is a white woman of 31 years old, with a child of two years old. She describes herself as a housewife. They define intellectual disability as an interaction between the organic impairment of the disabled individual and the context in which he or she is expected to function.

Factor description.

This factor emphasises the potential of the intellectually disabled person to learn (S14: -3): "*Putting a limit on learning is the biggest problem for me, because they cannot express themselves well and you can underestimate their understanding*" (S14: -3, P11). However, they are prevented from participating in "normal" life because they are not always treated well (S21: -3) and they are overprotected (S29: +2). The ability to live a normal life does not depend on improving skills (S12: -2), or on the organic deficit alone (S5: -2): "*What is a normal life? If you are happy and can live out your dreams, that is normal life*" (S5: -2, P11).

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[4] In this discussion, it is assumed that the child referred to is the intellectually disabled child.

Intellectually disabled people should be accorded autonomy and the right to choose for themselves (S30: +1) but this right is threatened by parents making decisions on their behalf (S19: +1) and by their limited ability to stand up for themselves (S10: +1). Although the child belongs there (S22: +3), the family limits their potential when it is overprotective (S29: +2): *"They can do more than we think (S25: +2). We should ask from them what they want to do. They know and you cannot decide for them. They don't get a chance to say what they want. We don't value their opinions"* (S30: +1, P11).

The capability of the individual is emphasised (S11: +2, S25: +2, S35: +3) and difference is cast in the light of a positive diversity: *"We are all different. You do not have to be like other people"* (S6: -2, P 11). Difference, which is rooted in an organic deficit, is mediated through social processes that stigmatise and exclude on the basis of this difference. This factor does not draw on spirituality or religion in its understanding of intellectual disability (S28: -1, 20:0).

This account differs from others (see Table 13) in the strong emphasis placed on getting married (S11: +2) and the rejection of gaining competence as a prerequisite for being normal (S12: -2). It is closely aligned with a social model understanding of disability in distinguishing between impairment and the disabling responses of society. There is a strong appeal to human rights in terms of autonomy and full participation in the community (see chapter 2).

Factor A2.2: An Innocent and Vulnerable Child of God

Factor outline.

This factor has an eigenvalue of 1.8 and accounts for 6% of the study variance. Four participants load significantly onto this factor. All of these participants are black. P5, a 27 year-old woman, is the caregiver of her deceased sister's child, who is four years old. She is unemployed. P19 is a 51 year-old woman who is a senior health professional, with a child of 23 years old. P26 is 55 years old, a woman who works as a community worker. Her daughter is 30 years old. Finally, P 28 is a 64 year-old man who is unemployed and has a child of 11 years.

The understandings of intellectual disability expressed by loading participants highlight the importance of caring for the disabled person, as a God-given duty: *"A gift from God. You are supposed to take care of her. We must take care of her and give her a good life because it is a gift from God. Because God gives us everything. You are supposed to love her"* (Comment, P5).

Factor description.

Intellectually disabled people are a gift from God (S28: +3) and are catered for within the family and the religious community (S20: +3, S23: +3). This factor is distinct from others (see Table 13) in the rejection of long-term relationships (S11: -3) and the belief that parents always act in accord with the disabled person's wishes (S19: -3).

Intellectually disabled people are not able to, nor should be expected to, take decisions for themselves. It is best for other people to decide. The powerful sense of duty that is imposed by God means that even financial support, in the form of a disability grant, should neither be asked for nor expected: *"When the child comes you don't think about the money. Think about the child as a gift from God"* (S24: -1, P6). There is an anxiety about relationships (S11: -3, S13: -1), reflecting a rejection of sexuality of intellectually disabled people in the light of their vulnerability. They do not know how to stand up for their rights (S10: +2) and so must be protected and can only work in sheltered environments (S33: +2).

The intellectually disabled person is not hidden from the community (S1: -1) but raising an intellectually disabled child can impose a burden on the family (S7: 0) and an alternative could be considered (S22: -1): *"They have different needs and therefore should be treated accordingly — not necessarily at home — taking care of their well-being. They are definitely not the same as other people"*(S22: -1, P19). Difference is interpreted in a spiritual sense as 'specialness' in the eyes of God: *"A gift from God. He loves them unconditionally"* (S28: +3, P19).

This account offers a limited view of competence as making a contribution in the home: *"If you learn her, how to do things, like wash the dishes, then she can do it"* (S35: +3, P28). Autonomy and independence is extremely limited in this account. An intellectually disabled person is a gift from God, and is special in His eyes. God requires that parents fulfil their duty toward this person by protecting them and preserving their innocence. The source of support for the child and the family, as well as the explanation for the disability, is to be found in God. This account resonates with some of the reasoning behind the institution (see chapter 2). It is philanthropic in its religious emphasis but custodial in the strong drive to protect the intellectually disabled person.

Factor A2.3: A Difficult Challenge to Their Family

Factor outline.

This factor has an eigenvalue of 3.00 and accounts for 10% of the study variance. There are six participants who load onto this factor at a significant level. The participants loading onto this factor are noted in Table 14.

Table 14: *Demographic Details of Participants Loading Significantly onto Factor A2.3*

Participant	Age	Gender	Race	Employment	Age of child
P7	44	F	White	Switchboard operator	7
P12	53	F	White	Book keeper	20
P20	50	F	Black	Health professional	Three children, 25,21 and 17
P22	47	F	Black	Unemployed	7
P23	44	F	Black	Unemployed	12
P29	48	M	Black	Unemployed	7

The participants define intellectual disability as an individual problem with reference to the cause, the deficit and the norm, as the following example illustrates: *"It is in the mind, not in the body or in hearing like deafness. The mind is a little bit slower and takes longer to learn, like Williams Syndrome"* (Comment, P7). These definitions emphasise organic impairment in the brain as the dominant feature of intellectual disability.

Factor description.

In this factor the intellectually disabled person is seen as a person very different to the norm (S36: -3). This difference is variously understood within the factor as being a) an altogether negative difference: *"The conduct of the children is not the same. It is totally different to the normal child. They will cry over nothing and do something funny e.g. take things and throw them around the house"* (S36: -3, P29), or b) a neutral fact of life: *"Intellectually they are not like other people because of the brain damage. The brain is the most important part of being intellectual. They are slow in learning; take more time to understand than a normal person"* (Comment, P22), or c) a challenge that must be accepted by families: *"It depends on parents/ caregivers. If they have accepted that they* *are gifts from God, then they will not be hidden. If they have accepted the disability. You accept them as they are if you trust God"* (S1: -1, P20).

They cannot take responsibility (S18: -3) and hence cannot make decisions and they need to be planned for: *"Disabled children need support from doctors. It is doctors and parents/caregivers who know exactly their problems. Therefore they should be able to decide for their future"* (S30: -3, P29). Parents and professionals can be trusted to take their views into account: *"My planning always takes place around my child. The school takes into account what they think. For example, they were concerned about the names on the buses, indicating it is a special school because they get teased in the community so they take this into consideration"* (S19: -2, P12).

This factor values the provision of therapy to make the most of the person's potential (S12: +3), but they are not able to live a normal life since the organic deficit prevents this (S5: +2): *"You can't lead a normal life with brain damage — that is a fact"* (S5: +2, P22). Every effort must be made to get the most out of him or her. This puts pressure on the parents/caregivers who feel that they should do more (see P7 above). They will do whatever they can afford to get help for their child: *"I'm not sure if there are places e.g. like A., I could take my child there if it is in his best interests. If they can take my child it might be better. If you can afford to do it, then you must if it helps him to develop"* (S22: -1, P22).

Given the severe restrictions that the biological deficit places on the child, it is irrelevant what labels are applied because the deficit is inherently biological (S38: +2). They are very likely to be abused (S17: +3):*"They are so trusting and do not have the insight into hidden motives. They are so gullible. They can be taken advantage of by unscrupulous people"* (S17: +3, P12). This adds another concern for parenting which requires vigilance and protection of the intellectually disabled person and supports the notion that they need to have decisions made for them and that the parents/caregivers and teachers are in the best position to do this (S19: -2).

The child is a gift from God in the sense that the reasons for intellectual disability are obscure but sent as a challenge to parents to fulfil God's wishes. At the same time, faith in God supports parents in this difficult task: *"I agree they are a gift from God because* *we don't know the cause or the reasons so we must trust in God. He cannot give you the burden you cannot carry. It goes with trust because you can't throw them away"* (S28: +3, P20).

An intellectually disabled person is vulnerable and incapable of independence. As such they are a challenge to families sent by God. They are very different from others and cannot be expected to take any form of responsibility for themselves. A2.3 is distinct from other accounts (see Table 13) in that the organic impairment, brain damage, precludes a "normal" life (S5: +2) and makes them very different to other people (S36: -3). Most notably, intellectually disabled children are seen as posing great difficulties to parents (S7: +3), which distinguishes this account from similar religious accounts in A2.2 and A2.6. It adopts a medical understanding of disability, where there is no distinction between impairment and disability and behaviour is seen as biologically determined by the organic deficit (see chapter 2).

Factor A2.4: A Person with Special Needs

Factor outline.

This factor has an eigenvalue of 1.31 and accounts for 4% of the study variance. There are two participants who load significantly onto this factor. P13 is a black woman, 41 years old who works as a community worker for disabled children and a *sangoma* (traditional healer). Her child is three years old. P18 is a black woman, 54 years of age, who is a teacher and has a child of 21 years.

The loading participants express understandings of intellectual disability that reflect the need to develop the limited potential as far as possible through love and patience: *"They are children that need love, care and development in areas of need. They are disadvantaged more than being disabled. Generally they are also human beings that have rights to be considered. Patience, love and care can bring good results"* (Comment, P18).

Factor description.

Within this factor, the intellectually disabled person is seen as having definite, quite recognisable differences from the norm (S27: -2, S36: -2). The response to this difference however, is not to overprotect the person, but rather to ensure that they are prepared for life through the proper training (S12: +3, S13: +2) which focuses on life skills: *"The child with intellectual disability is not doing very well concerning the brain. Sometimes if the child has intellectual disability, she always struggles at school. He has got barriers to learning and you must teach the child life skills and self-help, so he can do anything by himself"* (Comment, P13).

With the correct preparation and with consideration on the part of the community (S37: +3), the intellectually disabled person should be able to live a normal life (S5: -3). This life would be within the limits of protection from abuse (S17: +1) in sheltered settings (S33: +3) and with the ongoing support of the family. The intellectually disabled person is seen as having a responsibility to the family by being able to look after themselves and doing chores in the home. This is extended to their making a contribution to the family through the disability grant (S24: +1). Intellectually disabled people should be given all the opportunities to learn (S13: +2, S15: +2) since they are not scared of failure (S16: -3) and often they are not given enough learning opportunities (S4: +1).

Factor A2.4 is distinct from other accounts (see Table 13) in its assertion that organic impairment does not stop a person leading a normal life (S5: -3) but that normality is dependent on receiving all the professional help that they can get (S12: +3), which cannot always be provided within the family (S22: -2). It is also distinct in that it does not figure labelling as a negative practice (S38: +3):*"It does not matter what you call them because they will still have the disability although you can use other words and not retarded. I read a book which says we should say mentally challenged or disabled"*(S38: +3, P13).

Factor A2. 5: A Person to be Understood by the Community

Factor outline.

This factor has an eigenvalue of 1.5 and accounts for 5% of the variance in this study. There are two participants that load significantly onto this factor. P17 is a black woman, employed as a development worker working with disabled people. She is 56 years old and has a physical disability herself. Her child is 15 years old. P31 is 44 years old and has a child of ten years old. She is unemployed. Their understanding of intellectual disability emphasises both the limitations that it imposes and the potential that exists for overcoming these limitations.

Factor description.

This account proposes a strong positive role for parents/caregivers and teachers as knowing and acting in the best interests of the child (S19: -3). They are able to stand up for the rights of their intellectually disabled children (S10: -2). It does matter what labels intellectually disabled people are subject to (S38: -2): *“The better wording is people with intellectual disabilities, not calling them mentally retarded as it does not sound nice”* (S38: -2, P17). This account also rejects quite strongly the notion that it is difficult for parents/caregivers to raise a child with an intellectual disability (S7: -2).

The intellectually disabled person is like a child (S34: +3) but is not different from others at the level of a common humanity since he or she does not look different (S27: +3) or manifest difficult behaviour (S36: +2, S8: -2). They are able to learn and the onus is on the teachers, parents/caregivers and community to provide the right context for this to happen: *“They can do things like other children but might need more time and patience to understand things first”* (S8: -2, P31). Although they are viewed as being able to earn money to live on (S39: +3), this should happen under protective conditions, where communities are supportive: *“They can work in places and also be involved in the community projects as long as they are to be supported and be kept in a safe place”* (S33: +2, P13).

The responsibility for decision -making for the intellectually disabled person rests with the family and professionals (S19: -3, S30: -3) and parents/caregivers take this responsibility seriously: *“Everyone from parent to child should always be considered in decision -making about the child's future, both the child and the parent can think and make their own decision, like any other person”* (S19: -3, P31). Despite their limitations, the intellectually disabled person can get married (S11: +1) and have their own home (S9: -2): *“People with intellectual disability can have their own home by being assisted and provided with the necessary support”*(S9: -2, P13).

Within this account the intellectually disabled person is normal within the constraints imposed by an organic impairment. If one is aware of the limitations that are imposed by the impairment, then “normal” behaviour and appearance is defined with respect to the realistic expectations placed upon the individual with an organic impairment. There is a community responsibility to be aware of this in that the community must be educated about intellectual disability. *"Awareness about the disability should be conducted at the communities so as to empower society not to abuse them or treat them badly"* (S17: 0, P13). This account is similar to that of A2.4 in the need for correct training but allows for a greater consideration of community integration. The intellectually disabled person is qualitatively different from others (see chapter 3) and must be judged accordingly – the community must adapt to this difference to provide learning opportunities and support for full participation in all aspects of life, including relationships.

Factor A2.6: A Blessing and a Gift from God

Factor outline.

This factor has an eigenvalue of 4.79 and accounts for 15% of the study variance. There are nine participants that load significantly onto this factor. Their demographic details are presented in Table 15.

Table 15: *Demographic Details of Participants Loading Significantly onto FactorA2. 6*

Participant	Age	Gender	Race	Employment	Age of child
P3	54	F	White	Secretary	33
P4	50	M	White	Yard manager	33
P6	49	M	White	Administrator	7
P8	45	F	Black	Company director	7
P10	41	F	White	Sales rep	20
P15	41	F	White	Personal assistant	9
P21	47	F	Coloured	Office assistant	Two children: 9, 17
P25	44	M	White	Company director	Two children: 9, 3
P27	54	F	Black	Unemployed	12

Overall, the understanding is one that recognises difference and does not see this as a bad thing but as overtly positive in some cases: *"They can learn to do most things but they are different. I feel that every day you learn so much more and they are truly a joy in life"* (Comment, P3).

Factor description.

There is a childlike quality about the intellectually disabled person in this account (S34: +1). They enjoy art, music and dance (S31: +3), they are loving (S26: +3) and can learn many things with patience and guidance (S35: +3). In their innocence, they are a gift from God (S28: +3):*"This is the one I agree with the most. The doctor told me at four months that she is Down Syndrome. They said I must abort. God chose my womb. He* *never makes a mistake. I accepted her as a gift from God. Insomuch that I love her"* (S28: +3, P27) and: *"Our daughters have been a blessing in many ways to many people and teach us new lessons of grace every day"* (S28: +3, P25). As a consequence of their innocent and loving natures intellectually disabled children are not difficult for parents/caregivers to raise (S7: -2): *"They are easier than normal kids"* (S7: -2, P15).

The intellectually disabled person, because of their childlike qualities is unable to take responsibility (S18: -2) and is often treated unfairly because of their innocence (S21: -3). Parents/caregivers, teacher and doctors have an important role to play in making decisions in their lives (S30: -1, S19: -1). There is a fear of exploitation of innocence in that the disability grant should not be used for the family (S24: -3): *"I don't receive a grant. It is nonsense they bring love into a family"* (S24: -3, P21) and: *"They bring a lot more into life than money. They bless us in ways that make us better humans"* (S24: -3, P25). The parents' love might be excessive and limit potential through over-protectiveness or through low expectations: *"For instance I can't let her make me some tea because I am scared of her burning herself. I have to watch her go to school. It's better when someone else teaches her. I am scared"* (S29: +1, P27).

In this account difference is seen as being marked (S27: -3, S36: -1) and the response to this difference is to provide as much help as possible (S12: +2, S23: +2) and to enjoy the unique contribution that intellectually disabled people can make, especially at a spiritual level. This account is similar to Factor A2.2 in that it figures the intellectually disabled person as innocent within a spiritual context. However, the emphasis is more on duty in A2.2 and more on the benefits and joys of an intellectually disabled child in A2.6. The religious element of A2.6 contrasts with that of A2.3 where the intellectually disabled person is seen as a challenge and a burden imposed by God. The perspective of a blessing of the disabled child is not prominent in my discussion of intellectual disability in chapter 3. It appears to be a uniquely parental view (held by a large proportion of parents in this study) and as such a marginalised account in intellectual disability discourse (see chapter 4 for the exclusion of parental perspectives).

Summary of Q-study A2

Within Q-study A2, one account focuses on human rights and autonomy, with the degree of protection and control offered by the family as an important issue. The other accounts make reference to religious and community values of acceptance and tolerance that can be contrasted with a fear of abuse and ill-treatment. A summary of factors is presented in Table 16.

Table 16: *Summary of Factors in Q-study A2*

	A2.1: A citizen with rights.	A2.2: An innocent and vulnerable child of God.	A2.3: A difficult challenge to their family.	A2.4: A person with special needs.	A2.5: A person to be understood by the community.	A2.6: A blessing and a gift from God.
Difference	Response to difference is the problem rather than difference per se.	Difference is intrinsic to the individual and requires special care.	Difference is intrinsic and organic. It determines everything else.	Distinct organic difference.	Distinct organic difference that limits achievement.	Distinct organic impairment.
Spirituality	Does not draw on this.	God given duty to care for one who is special. God will give support.	Challenge sent from God.	Not a feature.	Not a feature.	Blessing sent by God.
Competence	Fluid and open-ended.	Extremely limited.	Extremely limited.	Social and life skills must be developed.	Can develop competence for community living.	Not a feature.
Social inclusion	An important human right.	Continue to be hidden but need protection in society.	Cannot be included because of their vulnerability.	Full social inclusion.	Full social inclusion but community must be educated.	Not a consideration – family and church will provide.
Autonomy	An important human right.	Extremely limited.	Extremely limited.	Not so important in a caring community.	Limited decision-making but full participation in community life.	Limited because of innocence and vulnerability.
Family	Belonging but problems of overprotection.	Source of protection and care.	Pose a difficult challenge to the family.	Less important than the broader community.	Source of support and educators of the community.	Family benefits from the child, overprotective.

Q-study A3: Professionals

The data for the 33 professional participants were analysed as for Q-studies A1 and A2. The eigenvalues and percentage of variance accounted for by each factor is given in Table 17 below. The five-factor solution accounts for 54% of the variance with 31 of the 33 participants loading significantly at p < 0.01 onto a factor.

Table 17: *Variance Accounted for by Factors and Factor Loading of Participants in Q-Study A3*

Factors	Eigens	% variance accounted for by factor	Number of Q sorts loading onto factor at significance level 0.41 and participant numbers of loading participants in brackets
A3.1	3.26	10%	5 (3, 10, 14, 18, 27)
A3.2	2.96	9%	6 (29, 24, 19, 16, 9, 13)
A3.3	4.02	12%	7 (7, 8, 15, 17, 21, 26, 33)
A3.4	3.09	9%	6 (2, 23, 25, 28, 31, 32)
A3.5	4.64	14%`	8 (1, 4, 5, 6, 11, 12, 20, 22)
Totals	17.96	54%	32

I have named the factors below, referring to an intellectually disabled person. It will be noted that these factor names imply a desirable course of action in contrast with the more descriptive factors of Q-studies A1 and A2.

A3.1: A person to be understood and advocated for by professionals.
A3.2: A person to be unconditionally accepted by the community.
A3.3: A person restricted by a label.
A3.4: A person with an impairment who requires support.
A3.5: A person with a condition that is an object of expert knowledge.

The factor loading for each participant is once again indicated in Appendix I in Table 5 and the factor array in Table 6.

There are six items in this array that are statistically significant consensus items. These are noted in Table 18.

Table 18: *Statistically Significant Consensus Statements for Q-Study A3*

Statement	*A3.1*	*A3.2*	*A3.3*	*A3.4*	*A3.5*
2. Their disability is the fault of their mother because of something she has done wrong.	-3	-3	-3	-3	-3
9. They can never have their own home.	-3	-3	-2	-3	-2
21. They are always treated well and fairly.	-3	-2	-3	-3	-3
25. They can do more than many people think they can.	3	2	3	3	2
31. They can enjoy art, music and dance.	2	3	2	3	2
35.They can learn to do most things for themselves with time and patience.	2	2	3	2	3

These consensus statements show a rejection of blaming the mother (S2) and assert the capability of intellectually disabled people in that they can have their own home (S9). However, their abilities are often underestimated (S25) and they are generally not treated fairly (S21). With the right kind of teaching, they can learn to do most things (S35). There are no distinguishing statements for any of the factors.

In addition to the statistically significant statements, I applied the criterion of two or less ranking point's difference between the highest and lowest ranking to identify statements about which there was substantial agreement. These are noted in Table 19 below.

Table 19: *Statements that Reflect Substantial Agreement Across Factors for Q-Study A3*

Statement	A3.1	A3.2	A3.3	A3.4	A3.5
5. Brain damage that makes learning difficult stops them from living a normal life.	0	0	-1	-2	-2
7. It is very difficult for parents/caregivers to bring up people like this.	-1	1	-1	1	1
11. They can have a long term relationship or get married.	-1	1	1	1	0
13. They should be taught about friendship, marriage and having children.	0	0	1	2	0
16. They are scared of failing in learning.	0	-2	0	-1	0
24. They bring something into the family because they can get a disability grant.	0	0	0	-1	-2
26. They can give and take love.	1	1	3	2	2
28. They are a gift from God.	1	3	1	1	1
32. They treat other people with respect.	-1	0	1	-1	-1
38. It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	-1	-3	-2	-2
40. They cannot manage their own money.	-1	-2	-2	0	0

While most of these consensus statements cluster around a neutral position, there is general agreement that they can give and take love (S26) and that derogatory labels are harmful (S38). For Q-study A3 there is a much higher occurrence of agreement (six statistically significant consensus statements and 11 of substantial agreement) than for Q-studies A1 (with no statistically significant consensus statements and only three of substantial agreement) and A2 (with two significant consensus statements and three of substantial agreement). One reason that I would suggest for this agreement is that professional knowledge is formalised as a certain way of knowing with its own forms of discourse that constitute a disciplinary knowledge.

There are only three statements reflecting substantial disagreements using the criterion of five or more ranking points between the highest and lowest ranking in the factor array. These are presented in Table 20. These statements of substantial disagreement will be used in factor interpretation below.

Table 20: *Statements that Reflect Substantial Disagreement Across Factors for Q-Study A3*

Statement	*A3.1*	*A3.2*	*A3.3*	*A3.4*	*A3.5*
20. They are always made welcome in church and religious places.	-3	2	-1	-1	0
27. They look the same as other people.	-1	3	1	0	-2
33. They can only work in places where they get support and are kept safe.	2	-1	-2	-3	2

Note. The shaded cells represent the highest and the lowest ranking of the statement.

Factor A3.1: A Person to be Understood and Advocated for by Professionals

Factor outline.

This factor has an eigenvalue of 3.26 and accounts for 10% of the study variance. There are five participants who load significantly onto this factor, as indicated in Table 21 below.

Table 21: *Demographic Details of Participants Loading Significantly onto Factor A3.1*

Participant	Age	Gender	Race	Employment
P3	37	M	“Coloured”	Special school teacher
P10	45	F	Black	Special school teacher
P14	40	M	Black	Special school principal
P18	40	F	Black	Regular school teacher
P27	41	F	Black	Regular school teacher

Participants loading onto this factor understand intellectual disability as a difficulty within the individual, affecting their performance relative to the norm with a specific organic cause:

“Intellectual disability is as a result of brain dysfunction which is as a result of failure of some areas of the brain to work normally. This results to a condition that limits the individual to perform some of the set standards of normal functioning” (Comment, P14).

Factor description.

Intellectually disabled people are vulnerable to abuse and exclusion (S21: -3, S17: +3, S20: -3) from all domains, including those that should be most welcoming, the family, the church, schools: *“You'll find that even in religious places — PLACES OF GRACE — still people with severe disability (PSD) are not treated well and fairly. In black communities you still find that people link such issues to witchcraft”* (S20: -3, P3). They are even excluded from the disability rights movement itself: *“They are not always treated well or fairly. As such they do not benefit from what is meant to benefit the disabled community. Even in organisations for the disabled, they are not known. The slogan that 'nothing about us without us' is not real for them”* (S21: -3, P14).

They are capable of so much more if given the right opportunities (S4: +3, S25: +3), which include professional help as an important element (S12: +3). Without this help they will be neglected and abused, as others do not have the expertise and concern of the skilled professional. However, their competence is limited as they do not want to learn how to read and write (S15: -1) but rather they need to learn life skills (S35: +2). Competence does not extend to relationships since they cannot have a long term relationship (S11: -1) and do not necessarily need to be taught about relationships (S13: 0).

There is an emphasis on the interaction of the disability with the professional help offered, so that achievement in life is equally dependent on the extent of their difference from the norm and the way that this is dealt with: *“PSD are not given enough opportunities to experience the world like a normally developing child and subsequently this leads to an issue called learned helplessness whereby the PSD/ child with severe disability (CSD) does not see the need to do things for themselves — depriving them of learning new things, with the result that society views PSD/CSD as unproductive members of society and does not see the need to give them TIME and patience to learn or do anything. They are regarded as only in NEED of help and as a person who can't do something”* (S25: +3, P3).

Since they cannot be expected to take responsibility for their actions (S18: -2), they should be cared for and protected. Parents/caregivers and doctors have a role to play in making decisions for them (S19: -2, S30: -2). The responsibility of the community is to treat them better (S37: +2) and to avoid hurtful labelling practices (S38: -2): *"I wish people (parents/caregivers and teachers) can change their attitude towards people with intellectual disability because they are also the creation of God"* (S28: +1, P18).

Family support is not highly valued in this account with neutral scores for staying within the family (S22: 0) and always needing help from the family (S23: 0). Parents/caregivers are seen to be somewhat over-protective (S29: +1). Decision-making and child rearing with the support of professionals is given more validity than that of parents/caregivers alone and a position of advocacy for intellectually disabled people is adopted. The distinctive differences of intellectually disabled people expose them to the dangers of an ill-informed and sometimes abusive family and community. The difference that is based in organic impairment can be ameliorated by the development of limited competence through the application of professional skill. The notion of psychological expertise (see chapter 2) is apposite here as a superior form of knowledge that is highly valued. It has an ethical intention in protecting the disabled person from abuse.

Factor A3.2: A Person to be Unconditionally Accepted by the Community

Factor outline.

This factor has an eigenvalue of 2.96 and accounts for 9% of the study variance. There are six participants who load significantly onto this factor and they are described in Table 22.

Table 22: *Demographic Details of Participants Significantly Loading onto Factor A3.2*

Participant	Age	Gender	Race	Employment
P9	34	F	Black	Community worker
P13	54	F	Black	Special school teacher
P16	49	F	Black	Principal regular school (FSS)
P19	59	F	Black	Regular school teacher (FSS)
P24	44	F	Black	Regular school teacher
P29	37	M	Black	Regular school teacher

The understanding of participants loading onto this factor refers to the place of the disabled person in the school and the community with respect to the prevailing expectations in these settings. Intellectual disability is viewed as a problem that is already there in the community, affecting large numbers of children: *"It refers to children being unable to concentrate on their work, or of having the feeling of satisfaction, unable to speak properly (lapse of words), unable to solve problems related their level of age. Of paramount importance is for teachers who stay with children for longer hours to be trained about intellectual disability. Mostly we tend to think of disability in terms of physical. In our school almost about 60% fall in the category of intellectual disability"* (Comment, P29).

Factor description.

In this account, there is a rejection of difference as a feature of intellectual disability (S27: +3, S36: +2, S6: -2, S8: -2): *"They are the same as normal because they have feelings, can relate with others and play with other children"* (S27: +3, P29). Difference exists at a superficial level and this does not affect the common humanity of all people in the eyes of God: *"God created people as his image. They are human beings"* (S28: +3, P13). As such they are an integral part of the community and they are made welcome in community spaces (S20: +2):*"Children with disability are a part of our communities. They are not taken away, even the schools that help them learn are part of our communities"* (S1: -3, P29).

While issues of difference are played down, there is a concern that these children are not always treated well (S21: -2, S17: +1) and that they will always need the care and protection of their family (S23: +2). They are credited with the competence to have their own home (S9: -3) and long term relationships (S11: +1) as full community members. They need professional help (S12: +3) to help them to do more than generally expected (S25: +2) and to learn when taught appropriately (S35: +2). Expertise and differentiation are played down in this account and belonging is emphasised.

Factor A3.3: A Person Restricted by a Label

Factor outline.

This factor has an eigenvalue of 4.02 and accounts for 12% of the study variance. There are seven participants who load significantly onto this factor and these are described in Table 23.

Table 23: *Demographic Details of Participants Significantly Loading onto Factor A3.3*

Participant	Age	Gender	Race	Employment
P7	42	F	White	Health professional
P8	40	F	Black	Community worker
P15	49	F	White	Health professional
P17	38	F	Black	Regular school teacher (FSS)
P26	37	F	Black	Regular school teacher
P33	46	M	White	Regular school teacher

The understanding of intellectual disability of participants who load onto this factor demonstrates a rejection of intellectual disability as a fixed and unproblematic category and the emphasis is on support required rather than intrinsic deficit: *"The person with intellectual disability can achieve as much as any other persons without the disability with all passion, patience and perseverance to do something. Others can assist with positive attitude towards the persons with intellectual disability"* (Comment, P8).

Factor description.

This factor strongly rejects organic impairment as the reason for limited achievement. There are external limitations placed on the potential of people with intellectual disability (S14: -3) and labelling practices have a negative impact (S38: -3):*"A person who is not able to function 'normally' according to the level expected of a class (according to the law/rules as laid down by higher bodies). I however do not agree with this as I don't believe they should be labelled as this leads to negative labels e.g. stupid, 'dof' [dumb], special class"* (Comment, P33).

The capability of the person with the disability is emphasised (S33: -2, S40: -2, S9: -2, S8: -2, S39: +2, S35: +3): *"Given a chance they can be anything, because they have their own intelligences that are being ignored by most people. Their strengths need to be built on so that they can be independent"* (S35: +3, P17). Capability does not always develop into competence because they are not always well treated (S21: -3) and they are forced to conform in ways that are difficult for them: *"They are always treated as outcasts in our communities. It is not them who should try to be accepted, it is the community that is supposed to understand their situation"* (S6: -2, P26). They can be overprotected by their families (S29: +2) but this is where they belong (S22: +2), with the appropriate support:*“To take any person away from their family is tragic and cruel. Systems should rather be put in place to help everybody cope better”* (S22: +2, P21).

Within this factor, the identification of intellectual disability as a category is a problematic action, fraught with the danger of making people conform to a category that highlights difference rather than similarities. An emphasis on similarities rather than difference means that everyone should be treated in the same way: *“Our similarities need to be highlighted and our differences set aside. After all that is how civilisation evolves positively and how our meaning of humanness and human divinity are defined”* (S37: +3, P33). At the same time, there needs to be recognition of diversity within categories as well: *“These statements are all generalisations. They stereotype and box people with a variety of strengths and challenges into a convenient label. Just as all so-called ‘intell-able’ people have strengths and weaknesses so too do people categorised as ‘intell-disabled’. One cannot actually make these statements 'en masse' - they may be true or false depending on the individual, ‘intell-abled’ or disabled”* (Comment, P21).

This account approaches claims of intrinsic difference with a high degree of scepticism reflecting a concern with labelling that constructs categories that come to be viewed in a negative light and limit the potential of human beings. This account is associated with a social model of disability as it distinguishes between impairment and the way in which it is dealt with. It goes further than this in figuring labelling practices as constructive of impairment and allowing for heterogeneity within the classification of intellectual disability. The account is similar to that of A2.1 but lays a greater emphasis on support than on human rights.

Factor A3.4: A Person with an Impairment who Requires Support

Factor outline.

This factor has an eigenvalue of 3.09 and accounts for 9% of the study variance. Six participants load significantly onto this factor, see Table 24.

Table 24: *Demographic Details of Participants Significantly Loading onto Factor A3.4*

Participant	Age	Gender	Race	Employment
P2	51	F	White	Special school teacher
P23	46	F	White	Regular school teacher
P25	44	F	Black	Regular school teacher
P28	38	F	White	Health professional
P31	54	F	White	Regular school teacher
P32	51	F	White	Health professional

The understanding of intellectual disability of loading participants is of an organic deficit in the child but the way that it is dealt with by the community and parents/caregivers either mitigates or exacerbates its effect: *"I hated to put a child in a box of intellectual disability and I was sceptical when the teachers say the child is stupid. There are different ways of learning but when I attended the conference in 2001 I understood better the reality of intellectual disability. Physical disability you can adapt for but intellectual disability you can't see. They are still learning. They are not cabbages. The concept of disability is like giving up hope so it bothers me"* (Comment, P31). The comment above is interesting in that it reflects a shift from a labelling perspective (similar to that put forward in the account of A3.3) to acknowledging the "reality" of intellectual disability, with it's effect of "giving up hope".

Factor description.

This account acknowledges the existence of an organic difference that impacts on learning. The organic impairment is exacerbated by negative attitudes: *"Brain damage makes learning difficult — that part I agree with but it does not have to stop anybody from leading a normal life. People's attitudes stop others from leading a normal life"* (S5: -2, P2).

The likelihood of abuse is rated very high (S17: +3): *"If you look at the media you will find many reports of rapes and abuse and sometimes you will find a social worker fighting for the chained child"* (S17: +3, P25). It is not only restricted to physical and sexual abuse but is seen to include a lack of educational opportunity: *"Teachers and parents/caregivers have low expectations from these children. They do not provide challenges"* (S25: +3, P2) and a disregard for their point of view (see P23): *"Other people make decisions for them and treat them as if they cannot do anything in the way they think"* (S21: -3, P23).

However, despite this level of capability, they are unable to take responsibility for their actions (S18: -2):*"Of the learners that I have taught, most were unable to take responsibility for their actions, often they would blame someone else or fabricate a story"* (S18: -2, P23). This lack of responsibility should not prevent them from making their own decisions in their relationships with guidance where necessary (S13: +2, S30: +2, S11: +1): *"They need more guidance for some it comes naturally but others it doesn't"* (S13: +2, P28).

The effect of impairment is unfair treatment and abuse in the community and within families. The individual therefore needs to be taught how to protect themselves and supported in becoming autonomous, rather than acquiring specific skills. It is similar to Factor A3.3 with the major difference lying in the understanding of the limitation that the organic impairment imposes and the degree of abuse that the individual is subject to. A3.4 envisages a limit to learning (S14: +1), which is rejected outright in Factor A3.3 (S14: -3). The account of A3.4 rates the likelihood of abuse very high (S17: +3) whereas A3.3 is neutral. This account is very closely aligned to a social model of disability, but relies to some extent on notions of professionalisation and expertise.

Factor A3. 5: A Person with a Condition that is an Object of Expert Knowledge

Factor outline.

Factor 5 has an eigenvalue of 4.64 and accounts for 14% of the study variance. There are seven participants who load significantly onto this factor, as indicated in Table 25. It is worth noting that all of these participants have considerable professional experience in working within intellectual disability.

Table 25: *Demographic Details of Participants Significantly Loading onto Factor 3.5*

Participant	Age	Gender	Race	Employment
P1	34	F	"Coloured"	Special school teacher
P5	30	F	White	Special school principal
P6	61	F	White	Special school principal
P11	38	F	Black	Special school teacher
P12	54	F	Black	Special school teacher
P20	59	F	White	District psychologist
P22	45	F	"Coloured"	Health professional

The understanding of intellectual disability expressed by loading participants tends to be norm referenced and several refer to the therapeutic action required. The problem of intellectual disability is located in the learning capacity of the individual, which is deficient. This factor also makes reference to degrees of severity in their definitions: *"There are varying degrees of intellectual disability. Persons with mild-mod intellectual dysfunction NEED early assessment and intervention. Community integration is NB so that persons with intellectual disability may lead as near to normal lives"* (Comment, P22).

Factor description.

There is a concern about abuse and ill-treatment that informs this factor (S17: +3, 21: -3): *"Because they often look and act differently and are expected not to understand what is happening to them, they are often abused"*(S17: +3, P20). The family is implicated in abuse (29: +3, 19: +1) in not making the correct decisions for their children. People with intellectual disability are not considered to be responsible for their actions (S18: -3): *"Their level of cognitive functioning often excludes understanding the consequences of a decision"* (S18: -3, P20). However, this should not justify overprotection on the part of parents/caregivers, which is seen to be problematic in this account (S29: +3): *"Parents/caregivers often tend to be overprotective. Where children have an intellectual disability, parents/caregivers may not consider their children as independent but consider them as children even into adulthood"* (S29: +3, P22).

Because of their vulnerability and the fact that they do not know how to stand up for themselves (S10: +2), they need to be protected and kept safe (S33: +2). There is an acknowledgement of difference that should be accepted as a reality in dealing with intellectually disabled people (S37: +3, S27: -2, S36: -1,S6: -3): *"Why should the responsibility [for changing themselves] lie with the person with a disability? Everyone should be respected for who they are. Equal unique individuals"* (S6: -3, P22).

Since they are subject to abuse and the family cannot be counted upon, it falls to professionals to offer some protection. The importance of autonomy in this account relates to the important role of the professional which is to train and support the intellectually disabled person to monitor and protect themselves. This account favours the intervention of the professional in limiting abuse and designating the correct levels of protection and independence because they know about the disability: *"If colleagues in a work place do not understand intellectually impaired people, it could lead to problems.*

They need support as they may have to be told over and over again what is permissible and what is not" (S33: +2, P1).

This position is based on knowledge about the "true" nature of intellectual disability: *"Disabled candidates will never make a successful marriage because of their low mentality, low self-esteem and some are physically weak to bear children and can not manage themselves, even their monies. They are a danger to themselves"* (S11:0, P12).

This account is similar to that given in A3.1 but differs in that it ascribes a range of characteristics to intellectual disability as a specific condition that require certain therapeutic interventions. It also offers strong views on individual autonomy independent of the family, who might not act in the best interests of the intellectually disabled person. Intervention is based on knowledge about the "truth" of intellectual disability and the best therapeutic actions to be taken. This account therefore justifies claims to decide appropriate aspirations for competence and independence, given a relatively hostile and ignorant community and family, through recourse to a superior knowledge of intellectual disability. There is an element of advocacy for the rights of the intellectually disabled person within this account as the "truth" needs to be disseminated amongst the ignorant parents/caregivers and community.

Summary of Q-study A3

In this study there is a concern with the impact of organic impairment in Factors A3.1, A3.4 and A3.5. Factors A3.2 and A3.3 provide little consideration of impairment focusing on community and labelling practices respectively. There is a cross cutting concern with ill-treatment by families and communities. The summary is presented in Table 26.

Table 26: *Summary of Factors in Q-study A3*

	A3.1: A person to be understood and advocated for by professionals.	A3.2: A person to be unconditionally accepted by the community.	A3.3: A person restricted by a label.	A3.4: A person with an impairment who requires support.	A3.5: A person with a condition that is an object of expert knowledge.
Difference	Organic difference is compounded by unfair treatment.	Difference is only superficial within a shared common humanity.	Difference is constructed by the way we categorise and label.	Disability is ‘real’. It places limitations on a person.	Impairment of different severity with different impact.
Spirituality	They require but are often refused spiritual care.	Claim to equality, fair treatment and belonging as God’ s children.	Not a feature.	Not a feature.	Not a feature.
Competence	Limited competence can be developed.	With professional help, they can be competent to live in the community.	Fluid and open-ended depending on opportunities.	Limited by the disability.	Depends on severity.
Social inclusion	High degree of exclusion and abuse.	Integral part of the community.	Limited due to negative labelling and societal attitudes.	Limited due to negative labelling and societal pressures.	High degree of abuse requiring protection.
Autonomy	Very limited.	Must be protected from unfair treatment.	Restricted by negative views of intellectual disability.	Restricted due to the disability.	Self-governing individual must be developed for a better quality of life.
Family	Family does not always act in best interests. They need professional guidance.	Community is more important than family.	Overprotective and needing support.	Viewed as neutral.	Can be abusive. Professionals know the truth about intellectual disability and must educate others.

Q-study A4: Second order factor analysis

As was noted in chapter 5, the second order study serves as a means of comparing the Q-studies conducted using Q-set A, that is Q-studies A1, A2 and A3. The factors from these studies were entered as Q-sorts for the second order study. I excluded Factors A1.2 and A1.2A because they each had only one significantly loading participant and have been exhaustively discussed in the section on Q-study A1. The resulting factors are described as for Q-studies A1, A2 and A3.

A four factor solution was preferred for this study as providing significant factors, accounting for an adequate percentage of variance and allowing all the Q-sorts to load significantly onto a factor. The second order study yields a new factor array that provides the best estimate of the loading of the various first order factors. It represents a reduction in the variation that was reflected in the three first order studies. The factors with eigenvalues, variance and number of Q sorts loading is shown in Table 27:

Table 27: *Variance Accounted for by Factors and Factor Loading of Participants in Q-Study A4*

Factors	Eigens	% variance accounted for by factor	Number of Q sorts loading onto factor at significance level 0.41. The Q-sorts are factors from the first three studies. They are listed in brackets.
A4.1	1.62	10%	3 (A1.1, A1.4, A2.5)
A4.2	1.96	12%	3 (A2.1, A3.3, A3.4)
A4.3	3.9	24%	7 (A1.3, A1.6, A2.2, A2.3, A2.6, A3.1, A3.5)
A4.4	1.70	11%	3 (A1.5, A2.4, A3.2)
Totals	9.18	57%	16

I have named the factors as follows, referring to discourses rather than accounts
Factor A4.1: Interactive discourse.
Factor A4.2: Social model/human rights discourse.
Factor A4.3: Medical model/religious discourse.
Factor A4.4: Community/religious discourse.

The factor loading for each of the Q-sorts and the factor array for this study are presented in Table 7 and 8 respectively, in Appendix I. There are seven consensus statements for Q-study A4, presented in Table 28. These statements represent the common understanding held by all the participants in all three studies.

Table 28: *Statistically Significant Consensus Statements for Q-Study A4*

Statement	A4.1	A4.2	A4.3	A4.4
2. Their disability is the fault of their mother because of something she has done wrong.	-3	-3	-3	-3
7.It is very difficult for parents/caregivers to bring up people like this.	0	0	0	-1
8. They often find it hard to behave or act in the right way.	-2	-2	1	-2
25. They can do more than many people think they can.	2	3	2	2
31. They can enjoy art, music and dance.	3	2	3	3
32. They treat other people with respect.	1	0	1	1
35. They can learn to do most things for themselves with time and patience.	2	2	3	2

There is general agreement that the mother is not to blame and a neutral stance about whether it is difficult for parents/caregivers to raise a child with intellectual disability. There is general disagreement that they find it hard to behave in the correct way. An overall positive image of intellectual disability is presented where they are able and willing to learn with the right kind of instruction. There are no differentiating statements for any of these factors. As an aid to factor interpretation I also present statements where there is substantial agreement (no more than two ranking points between the highest and lowest scoring factors for each statement) in Table 29 below.

Table 29: *Statements of Substantial Agreement across Factors in Q-study A4.*

Statements	A4.1	A4.2	A4.3	A4.4
4. They have not had enough of the right chances to learn.	-1	1	1	-1
5. Brain damage that makes learning difficult stops them from leading a normal life.	-1	-2	0	-1
6. They must try very hard to be more like other people.	0	-2	-2	-2
9. They can never have their own home.	-1	-3	-3	-3
11. They can have a long term relationship or get married.	0	1	-1	1
13. They should be taught about friendship, marriage and having children.	1	2	0	1
14. They will reach a limit to what they can learn.	-1	-2	-1	-2
15. They want to learn how to read and write.	3	1	1	2
21. They are always treated well and fairly.	-1	-3	-3	-1
22. They should be brought up within their families no matter what special needs they might have.	2	2	0	0
34. They can be thought of children in many ways.	1	-1	0	0

It is clear that there is a much higher degree of agreement for this study than for any of the others, since there are no statements with a high degree of disagreement. The above consensus indicates general agreement across all four factors that intellectually disabled people should be able to have their own home (S9), that their ability to learn is not limited (S14) and that they do not have to be like others (S6). However, they are generally subject to unfair treatment (S21).

Factor A4.1: Interactive Discourse

Factor outline.

This factor has an eigenvalue of 1.62 and accounts for 10% of the study variance. There are three Q-sorts (factors from Q-studies A1, A2 and A3) loading onto this factor:
A1.1: A competent person.
A1.4: An (ir)responsible person.
A2.5: A person to be understood by the community.
The overall connotation of the above is that competence and social inclusion have a specific relation to each other. Competence is created in social contexts, depending on both the application of the intellectually disabled person to the task and the support offered by the community.

Factor description.

This factor emphasises the desire to learn (S15: +3, S13: +1) and the capability of people with intellectual disability (S31: +3, S35: +3, S39: +3, S25: +2). They are able to have their own home (S9: -1) and are not likely to be poor (S3: -3) because they can earn and manage their own money (S39: +3, S40: -2). They are fully-fledged community members, entitled to participate in all arenas of community and family life. However, competence is not easily attained since they are scared of failing in learning (S16: +1).

Social inclusion does not depend on the autonomy of the individual, who can be thought of as a child in many ways (S34: +1), but rather it is the responsibility of parents and professionals who consider their needs and wishes (S19: -3). These wishes can be expressed since intellectually disabled people can stand up for their rights (S10: -2). For this reason, social inclusion within the family is of the utmost importance (S22: +2) and intellectually disabled people are not hidden away (S1: -2) but will always need the help of their families (S23: +1). While they will always need help from the family and in the work place (S33: +1, 23: +1), the disabled person can make a contribution to the family with the disability grant (S24: +2).

Difference from others is not important as they look and act like others (S27: +2, S36: +2) and can be expected to behave in the right way (S8: -2). Organic impairment is not a barrier to leading a normal life (S5: -1) and neither is therapeutic help a prerequisite for normality (S12: 0). Negative labels are rejected (S38: -2) as they can have a harmful effect over and above any organic deficit.

The nature of the impairment is open-ended and dynamic, since with the right kind of support, social inclusion and self-application, there is no reason for them not to be independent and socially integrated. Thus, support is an important element here, but it is not related to expertise.

There are three factors loading onto this second order factor and two of these arise from Q-study A1, which was conducted with intellectually disabled people and none from professionals in Q-study A3. The greater emphasis on competence and inclusion than on autonomy situates the disability as a community and family concern, rather than the property of the individual. This is not a professional discourse and looks to families and communities in supporting intellectually disabled people. This discourse will be further explored in chapter 8 and constitutes a marginalised perspective in the dominant understandings of intellectual disability.

Factor A4.2: Social model/Human Rights Discourse

Factor outline.

This factor has an eigenvalue of 1.96 and accounts for 12% of the study variance. There are three Q sorts loading significantly on to this factor. These loading Q-sorts (first order factors) have been named as follows:
A2.1: A citizen with rights.
A3.3: A person restricted by a label.
A3.4: A person with an impairment who requires support.

Factor description.

The intellectually disabled person is capable (S35: +3, S14: -2) but their competence is restricted by prevailing beliefs in their incapability (S25: +3), the way that difference is understood (S37: +3) and the lack of learning opportunities (S4: +1). There is no limit to their learning potential (S14: -2) but limitations are imposed by society (S25: +3). The impairment itself does not prevent them from living a normal life (S5: -2) and therapeutic intervention is not a necessary requirement for normality (S12: 0).

They are autonomous human beings with the same rights and wishes as anybody else (S26: +3, S13; +2, S22: +2, S31; +2) but sometimes they are prevented from achieving autonomy by over-protective parents (S29: +2) and other people making decisions for them (S30: +1). Competence, within this account, is more directed toward the achievement of autonomy than with the acquisition of skills. Learning how to read and write (S15: +1) is less important than having their own home (S9: -3) and working in mainstream settings (S33: -2). It is perhaps for this reason that professional help is not highly valued (S12: 0).

The reasons for social exclusion do not lie within the individual's incompetence but they are excluded because they are poorly treated (S21: -3, S17: +1) and because people do not always look at their capabilities (S37: +3). Their inclusion is fragile, as they are not even made welcome in church (S20: -1). Intellectually disabled people look the same as others (S27: +1) and do not find it hard to behave in the right way (S8: -2). However, difference is not entirely denied, as they are not always the same as other people in the way that they act (S36: -1) and they do not take responsibility (S18: -1).

In this view, the organic impairment is viewed as existing within the individual (except in the one constituent factor, A3.3), but it is not this impairment that constructs the problem of intellectual disability. This is created by social practices that stigmatise difference and attribute incompetence and dependence to the intellectually disabled person. The capability of the disabled person is emphasised and the cause for incompetence is sought in low expectations and prejudice. The outcome of this discourse is societal change that accepts difference and adopts a political agenda to ensure inclusivity regardless of levels of competence. This discourse is closely aligned with the social model account presented in chapter 2 and draws on claims to human rights and autonomy for the intellectually disabled person.

Factor A4.3: Medical Model/Religious Discourse

Factor outline.

This factor has an eigenvalue of 3.90 and accounts for 24% of the study variance. There are seven Q-sorts (first order factors) that load onto this factor. These are listed below:
A1.3: A person requiring special care and love.
A1.6: A stereotyped person.
A2.2: An innocent and vulnerable child of God.
A2.3: A difficult challenge to their family.
A2.6: A blessing and a gift from God.
A3.1: A person to be understood and advocated for by professionals.
A3.5: A person with a condition that is an object of expert knowledge.
All of these factors view intellectual disability as a thing apart, an object for divine or professional intervention.

Factor description.

Intellectually disabled people are a gift from God (S28: +3). As such intellectual disability is seen in a positive light and they can enjoy arts (S31: +3) and can give and take love (S26: +2). They are more competent than they are usually given credit for (S35: +3, S25: +2). This competence can be achieved in the face of real difference (S27: -2, S36: -1, S8; +1) with professional help (S12: +2) and a lot of help from the family (S23: +2), but it is a limited competence that does not extend to relationships (S11: -1, S13: 0).

They are not expected to take responsibility (S18: -3) so it falls to the parents and doctors to decide (S30: -2) and plan for them (S19: -1). This is particularly important since there is a high likelihood of ill-treatment (S21: -3) and abuse (S17: +2).

This discourse highlights the biological constraints that limit the competence of intellectually disabled people. These constraints should be addressed by therapeutic and specialised intervention as far as possible. However, the biological impairment precludes the assumption of normality and care and protection will be required once the limits of possibility are reached. This discourse accords with the medical model and professional expertise is highly valued.

The medical model is bolstered by reference to Christian discourses of innocence, duty and love. In this sense it is redolent of a philanthropic discourse as noted in chapter 3. The will of God is invoked both as an explanation for the random nature of the incidence of the disability and as an imperative for providing care and protection. The outcome of this discourse is the construction of protective and therapeutic mechanisms that shelter the individual from the rigours of every day life. In this configuration, I discern the operation of pastoral power providing an ethical rationale for the discipline of the intellectually disabled subject (see chapter 2).

What is also interesting to note is that this is by far the most heavily loaded factor with seven first order factors (A1.3, A1.6, A2.2, A2.3, A2.6, A3.1, A3.5) loading onto it. These factors are drawn equally from all participant groups, including intellectually disabled adults themselves, with Factor A1.6 perhaps being considered as a form of resistance to the application of pastoral power.

Factor A4.4: Community/Religious Discourse

Factor outline.

This factor has an eigenvalue of 1.70 and accounts for 11% of the study variance. There are three Q-sorts loading significantly onto this factor. These are listed below:
A1.5: A person discriminated against.
A2.4: A person with special needs.
A3.2: A person to be unconditionally accepted by the community.
All of these factors view intellectual disability as calling for special love and care within a religious value system. It differs from A4.3 in that love and care are valued above professional knowledge.

Factor description.

The intellectually disabled person is not different from others in significant ways (S27: +2, S8: -2, S6: -2, S36: +1). They are part of the community in that they are not hidden away (S1: -3) and they are always made welcome in church (S20: +3). They should be able to do all the things that other community members are able to do in having their own home (S9: -3) and a long-term relationship (S11: +1). It is therefore essentially similar to the relational discourse of A4.1. The difference is the high value placed on religious values (S28: +3) and the need for professional help (S12: +3). The responsibility of the community is to love and care and within this context issues of competence will be resolved, with no need for fear of learning (S16: -3). The role of the family is not as central as that posed in A4.1 (S24: 0, S22: 0, S19: 0).

Within a religious and community context, difference does not count for a great deal. We must learn to accommodate this difference in the caring community. There should be no necessity for care and protection if the right community values prevail. The ideal outcome of this discourse is a community that is educated about intellectual disability. In this sense the concept of *ubuntu* can be invoked, an African concept of a person's relationship with their community. A person is respected for their humanity whoever they may be. Failure to do this diminishes not only the person who is disrespected but also the one who is disrespectful (Lorenzo, 2003). This differs from the social model discourse (A4.2) in that there is little emphasis on autonomy and human rights but rather one of obligation to care for those less capable members of society. It also differs from the medical / religious discourse (A4.3) in its acceptance of difference but draws on religious discourse to a large degree in support of community caring, with the church viewed as a highly significant community entity.

Summary of Q-study A4

Interactive discourse.

The intellectually disabled person is in the process of becoming competent through interaction. The judicious provision of support in this process is paramount and supersedes considerations of autonomy and independent decision-making. However, intellectually disabled people must also take responsibility for their own learning. Social inclusion and interaction is crucial to the development of competence.

Social model/human rights discourse.

The intellectually disabled person has a right to education in a socially inclusive context regardless of the level of severity of the impairment or their social competence. Since autonomy is of the greatest importance, education should be aimed at supporting its development. While the existence of impairment is not in doubt, the impact of this on the development of competence is not apparent in advance. The likelihood of abuse and ill-treatment must be combated through education in human rights for those around the intellectually disabled person.

Medical model/religious discourse.

The competence of an intellectually disabled person is limited by organic impairment. They are likely to be abused and ill-treated because of their innocence and incompetence. Education therefore requires the application of specialised techniques to make the most of the impaired intellect and then care and protection must be put in place. It is not likely that they will develop autonomy and therefore skills in this area are not important.

Community/religious discourse.

Everyone in the community has some kind of problem and for an intellectually disabled person this problem is limited competence due to intellectual impairment. They still belong within the community and they must learn how to conduct themselves as community members. This requires the acquisition of skills just as much as education of the community to accommodate the difference that intellectual disability makes.

Discussion

While I have presented Q-study A4 as a summary and comparison between the accounts of intellectual disability from the three groups of participants in Q-studies A1, A2 and A3, there are important differences between these groups that need to be highlighted as they are not encapsulated in Q-study A4.

Q-study A1 is somewhat difficult to interpret and less clear-cut than the other studies. This could be attributed to the language difficulties and incompetence associated with those labelled as intellectually disabled. However, I take a different view and suggest that these accounts are diffuse in that they are less formalised than dominant discourses of human rights or professional expertise. As such, they are a form of subjugated knowledge that is not accorded value in terms of its truth claims (Foucault, 1984). The taken-for-granted nature of incompetence as an organic deficit is absent from these accounts and a struggle for competence, inclusion and fair treatment is evident. Disability is not something that inhabits the individual as a distinct entity, rather everyday struggles of being human and a community member are foregrounded. There is evidence for this understanding of disability in the fact that only six out of 22 participants identified themselves as intellectually disabled although they were all recipients of services for intellectually disabled people. Perhaps these participants can be seen as “people with diverse abilities who do not identify as disabled” (Gabel, 2002, p. 185) rather than simply as “intellectually disabled people”. Resistance to processes of subjectification (the imposition of identity from outside – see chapter 2) of intellectual disability is embryonic in form and appears in A1.6 as a rejection of stereotyping. All of the other accounts represent a subjectivisation of the individual constructing themselves as intellectually disabled subjects (see chapter 2). The account of A1.5 resists unfair treatment within the parameters imposed by subjectification processes. This will be discussed further in chapter 9.

Q-study A2 is notable for its heavy reliance on religious concepts and this will be discussed in some depth in chapter 8. The human rights account of A2.1 stands apart from the religious view in its emphasis on autonomy. This account is adopted by a specific group of parents who belong to the Down Syndrome Association Amathole, all of whom are white and economically well off. It can be viewed as an account of privilege in terms of the socio-economic status of the participants and their access to formalised systems of knowledge, such as inclusive education and human rights practices (see chapter 4). None of these accounts destabilise the concept of impairment to a significant degree and disability remains a property of the individual, which can be exacerbated or ameliorated through social processes.

In examining Q-study A3, the recourse to professional knowledge takes the form of a highly expert and differentiated form of understanding in accounts A3.1 and A3.5, associated (but not exclusively) with participants coming from special school settings. Account A3.3 is notable for the extent to which it undermines the organic impairment, referring to labelling as a practice that is productive of impairment.

Conclusion

In this chapter I presented accounts of intellectual disability drawn on by a range of participants in the Buffalo City municipality. I provided a summary and synthesis of these accounts in a second order study that identified four discourses. In so doing I have addressed the questions of what discourses are deployed in representations of intellectual disability. I shall follow the same procedure for educational practices in Chapter 7. I shall examine the effects of these discourses in Chapter 8.

CHAPTER 7: DISCOURSES OF EDUCATION FOR INTELLECTUALLY DISABLED PEOPLE

> It is not surprising that many people are perplexed by the changes that they have been confronted with. After all, the shift from apartheid education to Outcomes-based Education [OBE] and from special education to inclusive education is extremely complex. Apartheid education and special education were underpinned by particular assumptions, theories, models and practices. In order to move towards OBE, which is inclusive, one has to understand both the old and new assumptions, theories and practices to avoid repeating the old within the new framework. (Naicker, 1999, p. 67)

In chapter 6, factor interpretations were presented for a set of four Q-studies on the representation of intellectually disabled people. The purpose of that chapter was to address the research question relating to representation of intellectually disabled people. I shall now move to a discussion of discourses of education of intellectually disabled children, noting with Naicker (1999) above that change does not happen readily and old ways of doing things can be inserted within new frames.

In chapter 7, the findings from Q-study B are presented, exploring discourses of education for intellectually disabled people. As noted in the methodology section, only parents and professionals participated in Q-study B. The results of these two groups were combined into one on the premise, based on the interviews conducted, that the distinctness of discourses would depend less on the professional/parental status of the participants than on other aspects of diversity. The findings presented in this chapter address the second research question relating to educational discursive practices:
2. What discourses are deployed concerning the practices of education of those identified as intellectually disabled in Buffalo City, South Africa?

In this chapter I present the factors for Q-study B. I begin by presenting the statistical data from the Q-methodological analysis and then give a narrative account of each of these factors. I conclude this chapter by providing a summary of Q-study B factors and making the link to the third research question that will be addressed in chapter 8.

Results

A six factor solution was adopted as accounting for the largest amount of variance with clear factor structure and significant loading of all Q-sorts . The eigenvalues, percentage of variance accounted for and the number of loading participants is presented in Table 30 below.

Table 30: *Variance Accounted for by Factors and Number of Loading Participants for Q-Study B*

Factors	Eigenvalues	% variance accounted for by factor	Number of Q-sorts loading onto factor at significance level 0.33 ($p<0.01$)
B1	10.38	16%	19
B2	5.66	9%	15
B3	2.87	5%	5
B4	3.02	5%	6
B5	2.47	4%	3
B6	2.95	5%	7
Totals	27.35	44%	55

I have named the factors as follows:

B1: Inclusion as a human right.

B2: Special needs require special provision.

B3: Inclusive education is a dream of the future.

B4: Excellent special education as a right.

B5: Effective education must be tailored to the child’s needs.

B6: Special education keeps children safe.

In Table 9 in Appendix J, the factor loading of participants for Q-study B is presented. Significant Q-sort loadings are marked with an asterisk. Insignificant or confounded loadings are shaded. There are five confounded loadings (that is, the participant loads onto more than one factor at a significant level) and three insignificantly loading Q-sorts. These Q-sorts do not appear to arise from participants with common demographic features. Factor B3 is bipolar with one negatively loading sort (P26) and four positively loading sorts.

The factor array for Q-study B is presented in Table 10 in Appendix J. “Children and youth with intellectual disability” is used as the topic of the statements and is abbreviated as CYWID. There are no consensus statements for Q-study B. There are distinguishing statements for each of the factors and these will be discussed in the factor descriptions themselves.

Each account is given under sub-headings that cluster around the themes derived from chapter 4 but slightly different, based on the nature of the data (see chapter 5 for a discussion of themes in this study), namely:

Practices of inclusion/exclusion relate to the significance of educating intellectually disabled children in the mainstream schooling system and the associated support issues.

Practices of special education refer to the application of specialised techniques based on a technical knowledge of intellectual disability and can occur both in mainstream and special schools.

Practices of differentiation concern those that separate the intellectually disabled person from the norm and the finer distinctions that are made within this category.

Practices of professionalisation relate to the application of expertise in special or inclusive education.

Practices of family and community involvement concern how parents are located in educational practice.

Practices of advocacy clusters together those practices that aim to address unfair treatment of intellectually disabled people.

As an aid to factor descriptions, the comments made by participants loading onto a factor from the following sources are used to enhance and support the interpretation of that factor:

1. Responses to the question: “What is your general understanding of education of CYWID?” These are reflected as comments in the discussion below. The participant number (denoted by P) is given but not statement number, since these are general comments.
2. Explanations of their choices of the statements that they most agreed with and least agreed with. These are noted as emanating from a specific participant (denoted by P) with reference to a specific statement (denoted by S).

Factor B1: Inclusion as a Human Right

Factor Outline

This factor has an eigenvalue of 10.38 and accounts for 16% of the study variance. There are 19 participants who load significantly onto this factor. I, as the researcher, completed two Q-sorts as P34 and P62, both of which load strongly onto this factor despite the fact that they were done three months apart, at the beginning and the end of conducting participant interviews (see chapter 5). The loading participants present a diverse mix of parents and professionals. It is worth noting that all of the parents who load onto this factor belong to a parent support group, Down Syndrome Association Amathole. The participants are described in Table 31 below.

Table 31: *Demographic Details of Participants Loading Significantly onto Factor B1*

Participant	Race	Employment	Gender	Connection to ID
P1	'Coloured'	Special school educator	F	Professional
P3	'Coloured'	Special school educator	M	Professional
P7	White	Health professional	F	Professional
P8	Black	Community worker	F	Professional
P15	White	Health professional	F	Professional
P16	Black	Regular school, principal	F	Professional
P18	Black	Regular school educator	F	Professional
P21	Asian	District official/psychologist	F	Professional
P22	'Coloured'	Health professional	F	Professional
P29	Black	Regular school educator	F	Professional
P32	White	Regular school educator	M	Professional
P33	White	Health consultant	M	Parent
P34	White	Researcher	F	Parent & professional
P39	White	Switchboard operator	F	Parent
P43	White	Health professional	F	Parent & professional
P45	Black	Community worker	F	Parent & professional
P46	White	Housewife	F	Parent
P57	White	Business owner	M	Parent
P62	White	Researcher	F	Parent & professional

Factor Description

There are five statements that distinguish this factor from all other factors, as noted in Table 32.

Table 32: *Distinguishing Statements for Factor B1*

	B1	B2	B3	B4	B5	B6
13. The success of education of CYWID depends more on the approach of the particular school and the teachers than on the nature of the disability.	5	1	1	0	0	-2
18. CYWID in regular schools should be promoted with their peer group.	3	-3	-3	-3	-2	-5
21. It takes a very special and compassionate person with the right attitude to be an effective teacher of CYWID.	0	5	4	6	6	4
31. Over time all CYWID will be accommodated in what are currently considered to be 'ordinary schools'.	1	-5	5	-4	-4	-3
53. Human rights to equality for CYWID can only be achieved through education in inclusive education settings.	3	-5	-1	-5	-2	-3

This discourse is centred on practices of advocacy for intellectually disabled people (S53: +3) that locate the problem of intellectual disability within the school and society rather than within the individual (S13: +5). The requirement for all children to be educated together, as a way to overcome past inequality (S31: +1), outweighs technical and professional considerations. Thus teachers do not require special qualities (S21: 0) and learners can be promoted with their peers, even though they would not be doing work of the same academic standard (S18: +3). The regular school with an inclusive orientation that maximises existing supports and rejects deterministic views of disability is the preferred option.

Practices of inclusion/exclusion.

This discourse notes both the negative impact of segregation in education (S47: +4) and the potential positive impact of inclusive settings (S54: +6). The benefit is not only for the disabled child but extends to other children and teachers as well (S54: +6). Education of CYWID can improve education in the classroom and even have an impact on the broader social context: *"They are separated so teachers have a misconception that it is difficult to teach them. They are scared that they will fail and then they feel that is a very special skill. I don't agree with that. Once they start, they will see that it is not so difficult. It benefits the other children as well and makes them more compassionate. In the end this leads to a better society with less violence and crime"* (Comment, P43).

It is the response of the school that affects educational outcomes more than the disability itself (S13: +5). Regular schools can tackle inclusive education adequately (S17: +4), by making use of existing supports within the school (S23: +4). There is no reason to expect that CYWID would be better served, either academically (S48: +3) or socially (S52: -4) in a special school. However, the path to inclusion is not easy and this is a time of transition: *"Inclusive education can definitely be positive because teachers learn and other kids benefit too. It doesn't mean that it is easy"* (S54: +6, P46). Frustration is expressed with the slow pace of change in implementing inclusive education: *"It [education] is a must. They can only benefit. How long will we wait? Nothing gets done. It is seven years now since Education White Paper when K. was born. She will be too old to be involved"* (Comment, P39).

Practices of special education.

This discourse rejects practices of special education in favour of a flexible, differentiated curriculum that is built on good teaching practices that can (and should be) readily provided in the regular classroom. Much can be achieved within the regular curriculum with a "positive attitude", flexibility and making use of available supports (S17: +4, S23: +4, S48: +3). It is schools and teachers that need to change rather than learners themselves (S32: +3): *"The National Curriculum Statement is their [the teachers'] guide and they need to implement it with flexibility. Inclusive education policy is for ALL learners who experience barriers to learning to improve the quality of education"* (S44: -5, P7).The content of the curriculum should ensure the same learning opportunities for all children: *"A lot of people with intellectual disability have the capacity to read and write and do so much more than we are prepared to give them credit for and how would you know if you didn't try"* (S41: -3, P57).

Practices of differentiation.

One of the strongest features of this factor is the rejection of difference or "specialness" of CYWID (S45: -4, S22: -5, S52: -4). This discourse is not concerned with finer differentiations within the category of intellectual disability (S42: -4, S34: -6, S14: -4, S13: +5, S27: +5) that would qualify some for certain kinds of educational provision and exclude others: *"I think you are missing the whole point of inclusion if you only think it is for mildly disabled kids, because this means that you will still be excluding"* (S14: -4, P43). The preferred option is to keep an open mind about what the child is capable of and present him or her with the full range of opportunities: *"Placing a 'ceiling' on what society/educational authorities think a person can do creates a perception in the person and their family that that is indeed all they are capable of"*(S41: -3, P57).

Practices of professionalisation.

The rejection of difference constitutes intellectual disability as a part of normal diversity for classroom teachers (S24: -3, S25: -2) that would not require the application of specialist technologies such as IQ tests (S34: -6): *"IQ may be one factor to consider but I wouldn't rate it as very important-there are many other facets that make up and define a human being"*(S34: -6, P32). The skills of classroom teachers are deemed adequate: *"Admission requirements are not about testing [they are] more like just screening. Identify the problem, assessing and support with the consultation of the parents"* (S34: -6, P16). The valued professional skills within this account are those of the regular classroom teacher who should be able to differentiate the curriculum for CYWID.

Practices of family and community involvement.

The role of the family is central (S2: +6) and parents are seen to support schools to a moderate degree (S5: -2):*"A family must be together, we are stronger together and a child needs family support."* (S2: +6, P39). There is recognition of the difficulty that parents have in accessing education (S7: +4) in the context of the existing distinctions between special and regular schools. Parents are seen to want inclusion as long as their children's needs can be met (S50: +2). The support of the community is not evident (S10: 0) but within this discourse this is an aspect that must be developed through inclusive practice that contributes to social inclusion (S53: +3).

Practices of advocacy.

Schooling is seen as part of a human rights agenda that aims to minimise exclusion from participation in the community (S53: +3). Thus inclusive education is not an attempt to save money but rather an attempt to establish the rights of CYWID (S30: -5). This is a mutually constructive relationship where human rights should ensure that intellectually disabled people do receive education and education, in turn, promotes their human rights: *"The more people mix and recognise each others' strengths and weaknesses, the more tolerant our society will become. Therefore by segregating learners based on disability, other children will not learn about the strength there is in diversity"* (S47: +4, P7). The understanding of human rights within this factor is based on access and participation within a much broader social context than schooling alone (see discussion of human rights in chapter 2). Inclusive education has as one of its goals full participation of

CYWID (S1: +5, S47: +4, S53: +3). The right to education in integrated settings regardless of severity of disability (S27: +5, S14: -4) is asserted.

Factor B2: Special Needs Require Special Provision

Factor Outline

This factor has an eigenvalue of 5.66 and accounts for 9% of the study variance. There are 15 participants loading onto this factor. Their particulars are noted in Table 33 below.

Table 33: *Demographic Details of Participants Loading Significantly onto Factor B2*

Participant	Race	Employment	Gender	Connection to ID
P2	White	Special school, educator	F	Professional
P4	White	Special school educator	F	Professional
P5	White	Day care centre coordinator	F	Professional
P10	Black	Special school educator	F	Professional
P11	Black	Special school, educator	F	Professional
P14	Black	Special school, principal,	M	Professional
P23	White	Regular school, educator	F	Professional
P30	White	Regular school educator	F	Professional
P31	White	Health professional	F	Professional
P41	Black	Unemployed	F	Parent
P42	White	Sales rep.	F	Parent
P47	White	Personal assistant	F	Parent
P51	Black	Health professional	F	Parent
P58	Black	Horticultural worker	F	Parent
P60	Black	Unemployed	M	Parent

Factor Description

There are two items that distinguish Factor B2 from all the other factors. These are shown in Table 34.

Table 34: *Distinguishing Statements for Factor B2*

	B1	***B2***	*B3*	*B4*	*B5*	*B6*
17. Regular schools can cope with the education of the majority of CYWID if they focus on a flexible learning programme and a recognition of the learners' strengths.	4	**- 4**	0	0	6	2
20. It is impossible to teach CYWID in large classrooms with a linguistically and culturally diverse range of learners.	- 3	**6**	2	- 1	- 4	1

The special nature of teaching children with intellectual disability and the fear that their needs will be overlooked when they become one of a diverse group is noted (S20: +6) more strongly in this account than in any other. This "specialness" means that even changes to the regular school are strongly rejected as an option (S17: -4). In this configuration practices of special education and professionalisation are highlighted as the response to the problem of intellectual disability in education.

Practices of inclusion/exclusion.

This discourse places a premium value on the work of special schools (S58: +6, S31: -5) and figures inclusive education as constituting an abuse of children's rights to an appropriate education (S53: -5, S20: +6). Since their needs cannot be met in a setting of diversity, it follows that it would be unhelpful to accommodate all learners in regular schools (S17: -4, S12: +5, S46: +3). The participant comments below reject ordinary schools for intellectually disabled learners on the basis of severity and type of disability and the burden they place on teachers: *"What happens to the profoundly disabled? How will they cope? Not all CYWID can be accommodated in ordinary schools. They will not be able to cope as they need to be taught basic skills"* (S31: -5, P4).

"CYWID have such diverse and often complex problems e.g. physical, communication, perceptual (both auditory and visual) etc. that it is extremely difficult to cope with too large a group of learners" (S20: +6, P32).

"Educators have been placed under immense pressure with changes in assessment and moderation. Their administrative duties have increased phenomenally. This leaves very little time for the educator to give additional support to the CYWID in an inclusive setting" (S48: -6, P23). There will never be a fully inclusive system (S31: -5) because this is a system where it is impossible for CYWID to learn (S20: +6). Even in the context of change, inclusive education will not work (S32: -1) and even then parents would not want it to occur (S50: -2). There will always be insuperable problems such as promotion from one grade to the next (S18: -3) because they are unlikely to attain the required level of achievement. The impossibility of change is rooted in the static nature of the disability that precludes integration in regular settings by its very nature. Therefore special schools should be strengthened (S58: +6) rather than developing supports in the regular schools (S17: -4, S23: -1).

Practices of special education.

This discourse puts forward the need for a different curriculum for children with intellectual disability (S44: +1). Within this curriculum, issues around developing responsibility (S38: +2), communication (S39: +4) and providing sexuality education (S40: +3) and general life skills (S55: +4) are recognised as important. This type of curriculum must be firmly distinguished from that of the regular school: *"Programmes required by CYWID are totally different"* (S46: +3, P10).

Academic skills are also important (S41: -4) as this discourse values the development of individual competence highly. However there is recognition of a limit to learning in this respect: *"Although the academic side of learning is important and should be functional, there comes a point in education where it is more important to learn skills that will enable the person to live a functional independent life"* (S55: +4, P31). The educational programme should be structured (S37: +3), delivered in a separate learning site (S46: +3) and supported by professional therapy skills (S56: +4). The problem of education of CYWID is a technical one that must be addressed through specialised teaching and placement (S46: +3, S37: +3).

Practices of differentiation.

There is a distinction between those who should be in regular schools and in special schools. The severity of the disability is a consideration in the placement of the child in specialised settings (S59: -3, S14: +2). CYWID with severe disabilities are better served within a medical context than an educational one (S33: +2) and therefore special schools, with their focus on an educational curriculum, should not have to admit them (S59: -3).

The differentiation noted here concerns appropriate placement in special schools. Regular schools are ruled out as an option for intellectually disabled learners. Therefore the distinctions that need to be made are between intellectually disabled and "normal", and between severe to profound intellectual disability and mild to moderate intellectual disability. The former require some form of medical care and the latter should be placed in special schools. This is in contrast to the fine distinctions of Factor B5 below of different levels of disability and need.

Practices of professionalisation .

This discourse places a high value on the specialised settings where the right kind of teachers and professionals can ensure the right kind of education for CYWID: *"It takes dedicated teachers with a real and special interest in helping learners with intellectual disability to teach them"* (S21: +5, P4).

"Each learner should have an individual learning programme (ILP) to be drafted by the educators in consultation with professional support services which would assist the educator to be aware of the learners' areas of strengths and weaknesses to be considered when planning. This then will need a lot of planning according to the learners' needs, assessing progress (compiling progress reports) and giving extra lessons to those who need more support" (S46: +3, P14).

The expertise required is the knowledge of disability, the love of such children and the ability to move at a slower pace with more tolerance: *"The teacher will have a clear knowledge of how to deal with this sort of child"* (S37: +3, P 60).

"The teacher must have a very great love for the children. They cannot just teach them" (S60: +3, P60).

"Their teachers need to have a lot more patience, understanding more empathy and more tolerant of limitations. They need repetition and slower pace and basic life skills" (S21: +5, P42).

It is this combination of love and knowledge that is more important that any specific technical skills (S22: -2). The implication is that teachers of CYWID have special qualities and that they are special people made to do this kind of work. These qualities cannot simply be acquired through the development of skills. On the other hand, the skills of therapists are valued very highly (S56: +4). The implication here is that the psychological expertise of teachers lies in compassion and understanding whereas the medicalised gaze proper can only be exercised through the authority of the therapists (see chapter 2).

Practices of family and community involvement.

Statements that relate to the family's experience and involvement, the community and the impact of poverty tend to be valued as neutral within this account (S6: 0, S7: 0, S28: 0, S1: 1). The family and community are seen as being ignorant and not in the best position to help their children. Parents are minimally involved in their children's education (S3: 0, S5: 0). The special school is the most important resource for CYWID and should be able to cater to all their needs: *"Mostly among the African parents of intellectual disability learners are not aware of or understand that they can get support from professional people to alleviate the condition of the child. Educators in this institution have a better understanding of intellectual disability and the importance of a collaborative approach with all the support service in the classroom of the intellectually disabled learners"* (S19:

-6, P14). The nature of the disability is the major focus, rather than the community, which is a somewhat hostile environment (S10: -3). Other children in regular, community schools are often seen to be a negative force in the lives CYWID:*"I have seen children who were in mainstream schools who have moved to our kind of school. Most of them lack confidence and when asked what they disliked most at their previous schools, they all say that they did not like being teased by the other learners"* (S48: -6). The best interests of the child are distinguished from those of the family, who might not always be supportive of the child (S2: -1).

Practices of advocacy.

This discourse, like that of Factor B1, advocates for human rights but from a different premise and to different ends. The logic of human rights, here, is that equality requires specialised intervention for a very specific deficit – intellectual disability (see discussion of mainstreaming advocacy in chapter 4). Should this intervention, which is best done in specialised settings, not be provided then there would be an infringement of human rights: *"It is most important that CYWID have teachers and therapists that are trained and have the right experience to be able to give positively to each learner. Uneducated carers and teachers can do more harm than good"* (S54: -4, P5).

"The fact is that they would learn nothing in inclusive education because they would get lost. They need a different pace, more repetition. In inclusive education they would be ostracised and outcast. They have the right to the same education but not necessarily in the same environment. Their special needs must be catered for" (Comment, P42). Within this human rights frame, the right to participation is within "their own kind". Functioning outside of this grouping is deemed to be too difficult and threatening (S52: +4). The focus of rights is on accessing services to overcome the deficit. It has a narrow educational agenda and does not move outside of schooling.

Factor B3: Inclusive Education is a Dream of the Future

Factor Outline

This factor has an eigenvalue of 2.87 and accounts for 5% of the study variance. There are five participants loading onto this factor. Their particulars are noted in Table 35. These participants are all black and female. P26 loads onto this factor negatively therefore articulating an account which is directly at odds with the rest of the participants loading. Since this negative loading on the factor has only one participant, it is of dubious value according to the criteria for factor strength adopted in this study (see chapter 5 and also chapter 6, where I argue for the interpretation of such factors in Q-study A1). I shall therefore only discuss possible interpretations after a thorough analysis of the factor presented by the positively loading participants.

Table 35: *Demographic Details of Participants Significantly Loading onto Factor B 3*

Participant	Race	Employment	Gender	Connection to ID
P9	Black	Community worker	F	Professional
P19	Black	Regular school educator	F	Professional
P26 (negatively loaded)	Black	Regular school educator	F	Professional
P52	Black	Health professional	F	Parent
P63	Black	Unemployed	F	Parent

Factor description

The distinguishing statement for Factor B3 is presented in Table 36 below:

Table 36: *Distinguishing Statement for Factor B3*

	B1	B2	B3	B4	B5	B6
31. Over time all CYWID will be accommodated in what are currently considered to be ‘ordinary’ schools.	1	-5	5	-4	-4	-3

This is a discourse of belief in a goal of inclusive education for all children but recognises that it cannot happen now. As such it is both pragmatic and idealistic and adopts features of both Factor B1 (in support of inclusion) and Factor B2 (in the value given to special educational practices).

Practices of inclusion/exclusion.

Within this discourse there is a definite role for the special school (S58: +6) and it should be strengthened as a place where children will be accommodated in a transitional process toward inclusive education (S31: 5, S15: +3). There is a commitment to inclusion: *“Inclusive education is a good programme that helps children/adults with special needs to be accommodated to mainstream schools”* (S30: -6, P9). Inclusion is a means to achieving equality for intellectually disabled people: *“They are the same as others and separation from others leads to discrimination”* (S47: +2, P63).

However, in this discourse there are reservations about inclusive education. Children do not learn more in inclusive education (S48: -1) and CYWID feel more comfortable in special schools (S52: +1). The tension exists between the ideal of inclusion and the realities of implementation. Before this ideal can be reached, there is a lot of change that needs to happen (S32: +5). Teachers and communities need to be educated before there can be a move away from specialised centres: *"The teachers in the mainstream schools still need to be trained on how to accommodate children with mild intellectual disability"* (Comment, P9).

The role of the special school is oriented toward the provision of specialised services for severely disabled children (S59: +4, 27; +4, S56: +3, S33: -5). While specialised equipment and skills might be located within special schools, this does not mean that they hold the monopoly on caring and compassion and the necessary psychological expertise for CYWID (S60: -4, S21: +4).

Practices of special education.

The aim of the curriculum is to prepare CYWID to lead a useful life in sheltered employment (S35: +3). Thus reading and writing are not a priority (S41: +1) but learning responsibility (S38: +5) and how to communicate (S39: +3) are very important. *"It is not important for other people/children with disability to learn big numbers (maths) or big words. They just need to learn to take on responsibilities for their actions and plans for the future"* (S38: +5, P9). Dealing with discrimination (S1: +3) and being part of the community are valued outcomes in themselves (S47: +2).

Practices of differentiation.

This account presents strong support for catering for the education of severely disabled children (S33: -5, S27: +4): *"They can learn no matter how little they can learn. They can learn something so small rather than staying at home not learning anything. The state must provide. They deserve education just like the normal ones. They must provide relevant education"* (S27: +4, P52). Given the view that only children with a mild disability can be educated in the mainstream (S14: +4), the special schools would be reserved for severely disabled children: *"Because not all CYWID belong to the mainstream school. Others need to be placed at the resource schools"* (S14: +4, P9).

This differs from Factor B2 above in that there is a place for children with mild disabilities in the mainstream and they can benefit from inclusion. The differentiation that is important is between mild intellectual disability and severe to profound intellectual disability. The former belong in regular schools and the latter in special schools.

Practices of professionalisation

The importance of distinguishing between severely and mild or moderately disabled children is reflected in the high value that is placed on IQ tests: *"Intelligence test and IQ scores of CYWID are useful for developing realistic expectations for the child just because as soon as one sees these scores s/he is able to handle the learner in good manner as he knows that the child may be in need of support"* (S45: +6, P19). The professional skills that are valued in this account are not only located in special schools but can be found in the mainstream as well. They are just more developed in the special school and geared toward the more severely disabled. Critical to this distinction is the skill to distinguish between the degrees of severity and thereby to determine the correct placement.

Practices of family and community involvement.

The place of the family is on the periphery in this discourse (S2: -1). Parents are somewhat unsupportive (S5: +1) and tend to have low expectations of their children (S3: +1). They are moderately supportive of inclusion in an ideal setting (S50: +2). The nature of the community does not have a significant impact on education since poverty is rejected as a cause for educational failure of any kind (S4: -6, S16: -5) and social and cultural understandings do not impact on education (S9: -2).

Practices of advocacy.

Inclusive education policy is strongly supported (S30: -6) with the recognition that unless it is done properly, it will not serve a human rights agenda (S53: -1). There is also a strong recognition of the rights of severely disabled children to an education (S27: +4, S33: -5). This would take place within special schools and thus advocacy in this discourse would be directed at both the development of mainstream and specials schools.

Factor B3-

This factor is identified as the polar opposite of Factor B3. As such it prioritises poverty as a barrier to effective education of intellectually disabled people (S4: +6[5]) and constructs inclusive education as a ploy to get out of allocating proper finance to the education of disabled children (S30: +6). This then perpetuates a cycle of poverty as children come to be classified as intellectually disabled within poor communities (S16: +5). There is recognition of the higher costs of education CYWID (S29: +4). What is really needed is the eradication of poverty rather than special provision for severely disabled children, which is rated as not very helpful (S45: -6, S58: -6). While this factor poses some interesting avenues to explore in terms of the economic interactions with disability, I am uncomfortable with drawing too heavily on this as it is very tenuous and the comments from the loading participant are not always coherent. I shall therefore exclude this factor from further discussion while noting in passing that the relationship between poverty and intellectual disability could well be further explored.

Factor B4: Excellent Special Education as a Right

Factor Outline

This factor has an eigenvalue of 3.02 and accounts for 5% of the study variance. There are six participants loading onto this factor. Their particulars are presented in Table 37 below.

Table 37: *Demographic Details of Participants Significantly Loading onto Factor B4*

Participant	Race	Employment	Gender	**Connection to ID**
P24	Black	Regular school educator	F	Professional
P25	Black	Regular school educator	F	Professional
P35	White	Secretary	F	Parent
P36	White	Yard manager	M	Parent
P54	Black	Lawyer	F	Parent
P55	Black	Unemployed	F	Parent

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[5] Since this discussion is about the polar opposite of Factor B3, the signs of the ranking are reversed. See Chapter 6, Factor A2 and A2A for more..

Factor Description

The distinguishing statements for Factor B4 are presented in Table 38 below.

Table 38: *Distinguishing Statements for Factor B4*

	B1	B2	B3	B4	B5	B6
29. It is more expensive to educate CYWID than other children who are not disabled.	-2	-3	-4	3	-1	-4
38. Education of CYWID must develop their ability to take on responsibility.	2	2	5	-4	5	0
39. An important aspect of education for CYWID is to teach the child to communicate with others.	1	4	3	-4	5	5

A sharp distinction is drawn in this discourse between education that takes place in the home and education for the development of skills, that can be useful for employment, that is the responsibility of the school: *"It is not an important aspect to teach the child with disabilities to communicate with others. That can be taught at home. There is no special way of communication. They are responsible enough because they can do more than normal people do"* (S38: -4, S39: -4, P24). The value of this type of education is underscored by the fact that it will cost more than other types of education (S29: +3).

Practices of inclusion/exclusion.

The regular school cannot provide the right kind of education for CYWID because they will not be able to give the extra help required as they struggle to accommodate a range of learners (S22: +5) without teacher aides (S12: +3). CYWID are unlikely to benefit from inclusion (S48: -6) and there is no reason to expect that there would be a move into inclusive settings (S31: -4). Mainstream schools can also have a harmful impact, as they do not cater for specific skills development:*"Mainstream schools delay CYWID as they do not have options for these children e.g. skills development"* (Comment, P55). While inclusion is seen as a possibility if it is taken slowly (S51: +4), this is very remote since even children with mild disabilities will not benefit in the mainstream (S14: -5) and it is not the case that all children will be accommodated in the mainstream one day in the future (S31: -4). The mainstream school is seen as a place that is not safe (S11: +5): *"Disabled children are more safe in special schools than normal schools, especially those with severe disabilities because their safety cannot be guaranteed as some cannot hear or talk clearly"* (S11: +5, P24). The mainstream can also be seen as hostile: *"Mainstream schools don't want the CYWID. It is as if it is too much work for them"* (Comment, P36).

CYWID are better off in special schools (S52: +4) where there can be a direct focus on acquiring the necessary skills. These schools are highly valued (S58: +6) and their teachers have the necessary compassion and understanding of CYWID (S21: +6, S60: +5): *"I believe it takes a special and compassionate person with the right attitude to teach these special children"* (S21: +6, P35). These schools should not be treated as second to regular schools but should be well provided for so that CYWID can get all that they need: *"Special schools should be strengthened and supported. There should be all that is needed for these special children. The staff has a love of these children; you cannot take someone who does not understand. The staff there they understand"* (S60: +5, S58: +6). Given the expertise required, it is more expensive to educate CYWID (S29: +3): *"All schools must have this high tech equipment. The centres should have the best equipment because they cater for children with difficulties"* (S29: +3, P54).
"The cost of fees at special schools is more than mainstream schools" (S29: +3, P55).

Practices of special education.

The curriculum for CYWID should have academic learning as its priority since reading and writing is of much greater importance (S41: -6) than self-care and communication (S55: -1), which can be taught in the home. Aspects that relate to individual growth and autonomy are not valued within education (S38: -4, S39: -4). Strict discipline is desirable (S36: -5). What CYWID need are structured programmes (S37: +2) and a technically skilled teacher (S46: +2) situated within the caring environment of the special school (S60: +5). The purpose of education is to teach CYWID as much as possible to enable them to work in sheltered employment (S35: +3) and this includes helping them to address the stigma that they encounter in the community (S1: +4).

Practices of differentiation.

Since this account values academic learning, there is a sharp distinction made between levels of disability. More severely disabled CYWID should not be admitted to special schools (S59: -2) since they require the attention of nurses and doctors rather than schools (S33: +2). Therefore they are not entitled to an education at the cost of the state (S27: -3). The differentiation made in this factor is between intellectually disabled and "normal" and then between those amongst the intellectually disabled who can acquire literacy and numeracy skills and those who cannot.

Practices of professionalisation.

The expertise valued in this discourse is aimed at overcoming the deficit of the individual to enable them to read and write (S22: +5). These skills are accompanied by the necessary love and compassion (S60: +5, S21: +6). Educational techniques such as intelligence testing are valuable tools for guiding educational decisions (S45: +3):*"IQ scores really play a vital role as the educator can easily plan tasks for the learner effectively and really can expect good results especially if the teacher communicates well with the parents concerned"* (S45: +3, P25). A distinction can be detected between psychological expertise in handling the intellectually disabled child and medical and technical knowledge that is directed at the organic deficit itself.

Practices of family and community involvement.

The priority within this discourse is that CYWID develop skills through the correct teaching and communities and families are only a background to this process. The community is not a resource for CYWID (S10: -4) and CYWID are not being educated for full participation in the community (S35: +3), nor are they really expected to live and work in the community (S8: -3). The skills that they acquire in education are not intended to prepare them for employment in the community but rather in sheltered workshop settings (S35: +3). The intellectually disabled person and their family do not get a lot of support whether in the community (S10: -4) or in schools (S22: +5).

Practices of advocacy.

Fair treatment of CYWID is not attained though inclusive education (S53: -5). What they need is the proper funding of special schools to provide all the technical assistance required within a loving environment. Within this discourse advocacy is for equal access to an academic curriculum, which will certainly require additional spending as CYWID require professional and technical help that can be very costly. This amounts to a focus on providing external support rather than developing the agency and autonomy of CYWID themselves.

Factor B5: Effective Education Must be Tailored to the Child's Needs

Factor Outline

This factor has an eigenvalue of 2.47 and accounts for 4% of the study variance. There are three participants loading onto this factor. Their particulars are presented in Table 39 below.

Table 39: *Demographic Details of Participants Significantly Loading onto Factor B5*

Participant	Race	Employment	Gender	Connection to ID
P6	White	Special school principal	F	Professional
P17	Black	Regular school educator	F	Professional
P48	White	Entrepreneur	M	Parent

Factor Description

There are two distinguishing statements for this factor which are presented in Table 40 below.

Table 40: *Distinguishing Statements for Factor B5*

	B1	B2	B3	B4	B5	B6
10. There are many useful resources in the community that could support the education of CYWID in the local school.	0	-3	0	-4	5	-6
35. The aim of education for CYWID is to help them lead productive and useful lives in places for sheltered employment.	-1	-2	3	3	-6	4

Overall this is a discourse that resists generalisations about CYWID seeing them as a heterogeneous group, mainly on the dimension of severity. Practices of differentiation are highly valued since it through these practices that it is possible to determine exactly the needs of the particular child. As such, possibilities exist in the community to support certain learners (S10: +5) and a narrow view of education as only for sheltered employment is rejected (S35: -6).

Practices of inclusion/exclusion.

Within the discourse of B5, inclusion is viewed in a positive light (S54: +4), with provisos attached. It should proceed gradually (S51: +4) since it is a difficult task (S22: +3). Inclusion requires teacher training because there is more work involved (S25: +2) and without this training it places an unfair burden on the teacher (S24: +2). Parents would want inclusive education if it was done correctly (S50: +2) and it would help to reduce the stigma attached to intellectual disability (S47: +3). The key to distinguishing between inclusive and exclusive practice lies in the grading of the different levels of severity.

The good intentions of an inclusive education system are recognised:*“I think inclusive education is trying to help these learners: to make them part of their communities despite their disabilities, to help them to be accepted and be able to achieve in the future and be better people who are independent, to build on the intelligences they have”* (S30: -6, P17). However, there is a sense in which the regular schools are not playing their part:
“Advocacy is only reaching those who know what it is about in the first place. Regular schools are scared of it [inclusion] and feel inadequate” (S7: +4, P6).
“Schools don't want to take him because of his disability” (S7: +4, P48). It is special schools that know the truth about intellectual disability, but the knowledge could be transferred into the mainstream, if they were receptive to it, in cases where the disability is less severe.

Practices of special education.

The content of education has an important focus on life skills that would allow for participation in the community (S38: +5, S39: +5). Academic skills are less important (S41: -2): *“You should try and teach. It [reading] must be tried but this is not the be all and end all as they might not be capable”* (S41: -2, P6). The most important aspect of education is that it meets the needs of CYWID in an individualised way: *“It [education] is important and it is a right. It must be tailored and adapted to meet the needs of the child in terms of expectations, rate, and the goals of the parents that are realistic. One needs to consider a broad spectrum that balances all of these. Parents should be involved so as not to be unrealistic”* (Comment, P6).

Inclusion is for the less severely disabled (S14: +3) and special schools will always be needed (S58: +3) since some CYWID require a different curriculum (S44: +1) with a greater focus on life skills (S55: +1). Education should prepare them for employment that can be in the open market:*“Disagree with the 'sheltered employment' part of it”* (S35: -6, P7).

Practices of differentiation.

There is a distinction made between different levels of competence calling for different forms of education (S14: +3). Children who are very severely disabled do not belong in a special school:*"Some children are too severely disabled to benefit from the curriculum (NCS) i.e. if they don't have an interest to learn, is it fair to place them where their particular needs are for care and stimulation? Such a large demand for places at a special school means that you exclude others who can benefit. Social interaction can be great but ability to become involved is limited. There must be somewhere to draw the line. It is also very difficult with uncontrolled behaviour"* (S59: -5, P6). They do not require education at the cost of the state (S27: -3) since care is more appropriate than education. However, it is not necessarily the case that they should be excluded from educational environments (S33: -3) since the educational programme can be differentiated within these contexts. Professionals can identify multiple educational placements and methods, largely based on the dimension of specific needs of the individual. No single placement, such as regular schools will ever be able to accommodate all CYWID (S31: -4) because of these highly individualised needs. Therefore some CYWID, presumably those with a less severe disability, can be taught in large classes (S20: -4) and they do not always require a highly specialised form of education (S46: -4).

While severity of the disability or level of competence is important it is not the only consideration. IQ testing is not viewed as an important indicator of this competence (S45: -5, S34: -1) since it does not always give a fair reflection of the child's potential: "*The medical model is not always true because they don't take into consideration the learner's strengths. Given time the learner can progress and the tests remain null and void and the child can achieve more than the tests have stated*"(S45: -5, P17). However, it does have a role in identifying the right learner for the special school, as the mark of an underlying incapacity for learning that limits achievement: *"IQ is an important factor but not the only one. If the child is functioning on a low level and is deprived then it could be that the child could do more than they are doing. But if there is a low IQ score that doesn't come up with other issues e.g. vision or hearing then they are suitable for our school. IQ can show us how she should be performing in school"* (S34: -1, P6).

This discourse takes the view that special schools accommodate learners who should be in mainstream schools (S57: +4). More careful processes are needed for discriminating between those who belong in the different settings to ensure that they are properly placed. : *“In the ex-white department, we had school psychologists who would pick up through IQ tests then move kids into special class. Those kids did not come to our school. In the black and ‘coloured’ schools, they were not picked up earlier. They did not have special classes so they came to our school. FAS (foetal alcohol syndrome) kids are very difficult in the regular school. The behavioural problems come from kids who should not be here”* (S57: +4, P6). Thus social issues are an element of diversity amongst CYWID but deserve scrutiny only to the extent that they obscure the truth of an underlying biological impairment.

Practices of professionalisation .

Professional skills are required from doctors and psychologists to make fine differentiations between different degrees of severity and to prescribe appropriate courses of action within a tailored educational programme:*“The educators need to identify the learners’ strengths so that they can build on them. They need to make an individual support plan for each learner and support him. They need to work hand in glove with the parents so as to know the child holistically and build him”* (S17: +6, P17). In addition, teachers must have a special compassion (S21: +6) or skills (S22: +3) to teach CYWID but the setting in which this takes place is less important (S17: +6, S46: -4, S20: -4). The professional is tasked with identifying the true nature of intellectual disability in the individual and the judicious provision of educational technology to ameliorate this lack in the individual. However, despite all the professional expertise that is brought to bear on the individual, the educational provision cannot be expected to outweigh the disability in terms of positive outcomes (S13: 0).

Practices of family and community involvement.

There is mild agreement that CYWID should not be sent away from their family (S2: +1), but this depends on the circumstances:*“If a child is brilliant in maths, you would send him away to the best school, so too the intellectually disabled child if it is in his best interests”*(S2: +1, P6). Parents are viewed as not being completely supportive of their children’s education (S5: +1) and as having low expectations (S3: +1).

Practices of advocacy.

There is little place for a human rights perspective in this discourse. The problem of intellectual disability is a technical one, which requires specific skills in individualising learning to an increasingly fine degree so that the perfect match between the learner profile and the learning programme can be made.

Factor B6: Special Education Keeps Children Safe

Factor Outline

This factor has an eigenvalue of 2.95 and accounts for 5% of the study variance. There are seven participants loading onto this factor. Their particulars are presented in Table 41 below.

Table 41: *Demographic Details of Participants Significantly Loading onto Factor B6*

Participant	Race	Employment	Gender	Connection to ID
P12	Black	Special school educator,	F	Professional
P13	Black	Special school educator	F	Professional
P37	Black	Unemployed	F	Parent
P40	Black	Company director	F	Parent
P53	“Coloured’	Personal assistant	F	Parent
P59	Black	Unemployed	F	Parent
P61	Black	Regular school educator	M	Parent

The majority of these participants are black parents and the two professionals loading onto this factor are black educators at a special school.

Factor Description

There is one distinguishing statement for this factor, which is presented in Table 42 below.

Table 42: *Distinguishing Statement for Factor B6*

	B1	B2	B3	B4	B5	B6
32. Education of CYWID can only take place in the mainstream if there is transformation and change throughout the whole education system	3	-1	5	1	-1	-6

This discourse focuses on the need for protection of CYWID from a hostile community. In the light of the factor description below, it appears that this statement reflects a rejection of inclusive education in total. No matter how the system might be transformed, it will never be suitable for the education of CYWID.

Practices of inclusion/exclusion.

In this account there is a strong inclination toward special schools as opposed to regular schools for the education of CYWID. Rejection of regular schools is based on the understanding that teachers are not trained and the classes are too big:*"They must go to special schools, not to normal schools. The teachers in normal schools are not trained for the skills for this child. There are so many children in the class. There should be four or five because they don't listen. You must be patient"* (Comment, P40). For this choice to be a reality, there should be more specialised centres for them: *"There should be more support for them. More centres for them so they can feel comfortable. Not enough facilities for them"* (Comment, P53). These new facilities must be run by professionals and not parents (S6: -1) because specialised expertise is required.

The safety and happiness of CYWID is not well served in the mainstream (S11: +5, 52: +4): *"We are not guaranteed safety because other children will laugh at them. My child does not speak clearly. Even I cannot understand him all the time. They will laugh and not understand"* (S11: +5). The special schools should provide therapy (S56: +3): *"They need the therapic (sic) schools where there is no rush or extensive learning because of their handicap/disability"* (S56: +3, P12). The teaching skills for education of CYWID are significant (S22: +3). The situation in the mainstream presents a bleak picture for CYWID (S54: -2), even if parents manage to overcome the difficulty that they experience with admission (S7: +3).

Practices of special education.

The curriculum aims to teach life skills (S55: +2) that would ultimately prepare the child for work in a sheltered environment (S35: +4). CYWID require structured programmes (S37: +4):*"It is so that they know the goals. I would like to teach my child computer or switch board so she can have the skills"* (S37: +4, P59). They require strict discipline (S36: -3): *"CYWID would need more rote learning. Repeat the same things so that the child can grasp the concepts being taught. Rigid discipline should be good for them because they must make sure that they are strict and strong methods should be applied because they don't easily understand things"* (S36: -3, P61).

The focus of curriculum is to improve skills, such as communication (S39: +5) with independence and responsibility being of less significance (S1: +2, S38: 0, S40: -1, S41 -2) within a carefully constructed programme that provides safety, love and support.

Practices of differentiation.

Special schools should accept all children regardless of the severity of their disability (S59: +3). There is an implication that they should also accept those with less severe disability. Currently special schools do not have children who should be in the mainstream (S57: -3).

Practices of professionalisation.

IQ tests are important in guiding both the admission of learners (S34: +2) and developing realistic expectations (S45: +2). The compassion and safety in the special school are highly valued (S60: +5, S21: +4, S56: +3, S22: +3): *"I think one of the reasons that the staff of special schools will be well trained, they have got skills and have an understanding of how to treat the kids. The children of special schools have problems of disability; therefore you need to treat them with care. They also understand that those children, they can't cope. They have mental and physical problems. They cannot be harsh when dealing with them, rather they must be protected and secure"* (S60: +5, P61). The above quote highlights the importance of professional skills in "knowing disability" above the application of technical skills that might improve the competence and independence of CYWID.

Practices of family and community involvement.

The family is central in this discourse. The child belongs within the family (S2: +6):
"They are supposed to be there with their family and to the community" (2: +6, P37).
"They should never be sent away because they need this support and should not be isolated" (2: +6, P53). Special schools are places of choice for these children (S58: +6, S60: +5, S52: +4). The importance of the family and the special school arises because there is no support in the community (S10: -6) and the mainstream will never be able to accommodate CYWID (S32: -6). Parents are highly supportive of the school (S5: -5) because this is really the only resource that they have available to them in supporting their children: *"We are supportive. How can they say that?"* (S5: -5, P53).

"Here are not so many useful resources to support CYWID. They are still complaining about the infrastructure in our schools. They are still in need of transport, not enough teaching aids; we also need sports fields for disabled children, now they cannot be involved in sport. They don't have special books." (S10: -6, P61). There is even hostility in the community:*"There are no resources because in A. there is no support from the community. They only cater for normal children. The Indian man at the shop was harassing my child at the spaza shop. I told him you could see he is not normal. Why do you push him out of the shop? Why do you say to me that I can't look after the child?"* (S10: -6, P40).

Practices of advocacy.

The care and protection of a special school is what is needed. The autonomy of CYWID is not an important issue (S40: -1, S38: 0, S1: +2). An overriding desire to protect CYWID minimises the importance of autonomy and agency but there is advocacy for the right to protection and freedom from abuse for CYWID.

Summary of Q-study B

In this chapter I have presented a range of accounts of the education of intellectually disabled people. A summary of the resulting factor descriptions is presented in Table 43.

Table 43: *Summary of Factors in Q-study B*

	B1: Inclusion as a human right.	B2 Special needs require special provision	B3 Inclusive education is a dream of the future.	B4 Excellent special education as a right.	B5 Effective education must be tailored to the child's needs.	B6 Special education keeps children safe.
In/exclusion	Inclusion is a human right for all regardless of disability.	Inclusion violates the child's rights to appropriate education.	Inclusion is a good idea but a long way off in the implementation.	Separate but equal education is the preferred option.	In/exclusion are options to be decided on through professional consideration.	Exclusion from the community is necessary for their safety.
Special education	Adaptation of good teaching practice, not special education.	A different curriculum is required.	Separate curriculum for CYWID with severe disabilities.	Different curriculum with special teaching methods to ensure acquisition of marketable skills.	Individualised curriculum must be developed to meet specific child's needs.	Different curriculum with focus on life skills that prepares for sheltered employment.
Differentiation	Does not apply to individuals because all have the same rights. Differentiation takes place at the level of the curriculum.	Distinguish between CYWID and "normal", and between severe to profound ID and mild to moderate ID.	Distinguish between mild intellectual disability and severe to profound intellectual disability.	Differentiation between CYWID and "normal", between CYWID who can acquire literacy and numeracy skills and those who cannot.	Finely differentiated according to level of need based largely on severity of impairment.	Distinction between CYWID and others but not within the group.
Professionalisation	Rejected in favour of good classroom practice.	Teachers located in special schools provide love and knowledge, therapists provide skills.	Special schools have expertise with severe disability but skills exist in the mainstream for mild disability.	Specific expertise required to overcome the organic deficit.	Expertise to identify the real ID in the individual and to ameliorate this deficit.	Professional expertise is required to understand disability and protect with kindness and compassion.

Family and community	Supportive families and communities must be educated.	Do not have the necessary knowledge of disability. They should be educated by professionals.	Do not receive much consideration.	The acquisition of skills is a priority, more important than family or community issues.	Family and community contexts obscure, exacerbate or ameliorate the existing deficit.	Family and special school form protective barrier against hostile community.
Advocacy	This is central. Education must build autonomy.	Emphasises access to appropriate services as a right.	This is not a strong element here.	Focuses on providing external support and funding rather than autonomy.	This is not a strong element. Professional skill rather than advocacy.	Claims humans rights at a basic level – protection from abuse and compassionate treatment.

Discussion

The discourses presented above configure educational practices differently around different understandings of intellectual disability. Before going on to a discussion of how this operates and addressing my third research question, I shall compare these discourses. Practices of inclusion range from full inclusion regardless of severity (B1) to an outright rejection of inclusion in any circumstances (B6). It was noted in B1 that all parents loading onto this factor are members of DSAA. Only one of them is black and she is an employee of the association. In contrast, the parents loading onto B6 are all either black or "coloured". It is a feature of the South African education system that the majority of regular schools in East London catering largely for black learners are under-resourced and lack basic infrastructure (McKenzie, 2007). If parents envisage their children going to these schools, they have real concerns about the provision of education and the safety of these schools. White children, on the other hand, can expect to go to better functioning, so-called "former Model C" schools (that catered exclusively for white children prior to 1994). An aversion to inclusive schooling is more understandable in this context.

The discourse of B3 embraces elements of full inclusion but sees this as a future possibility. This represents something of a compromise between theoretical and moral principles and the real world, and is a position that reflects the need for appropriate support that will enhance participation. This aligns with Gabel's (2002) position that: "People with diverse abilities may need marked changes in curricula, teacher expectations, school buildings, social structures, and classroom organization in order to participate in classroom life." (p. 188). In this view the limitations of the real world to meet these requirements must be recognised in fairness to students. While all participants loading onto this factor were black and female, the significance of this is not clear.

Practices of special education are viewed in the light of whether they are exclusively the domain of special schools or can be located in the mainstream. In B5 there is readiness to spread these practices far and wide under the proper supervision of the authorities, whereas B4 locates them within a properly financed special school. The flexibility of B5 is indicative of a carefully regulated practice of inclusion through the importation of special education practice as noted in chapter 4. The curriculum as a central aspect of special education also varies from an emphasis on life skills (as in B6) to a demand for academic skills (B4), or a belief in the same flexible curriculum for all children (B1). Each of these perspectives has implications – and draws on – certain representations of intellectual disability and its relationship to the norm.

Differentiation is a feature of all these discourses, except B1, and varies from gross differentiation between those that belong in special schools and those that do not (B6) to the highly differentiated account of B5. B1 eschews differentiation of individuals entirely and looks to the curriculum for distinguishing between different learning needs. The degree of differentiation has implications for dividing practices that normalise individuals in the exercise of disciplinary power (see discussion on disciplinary power in chapter 2).

Professionalisation has emerged as a particularly interesting aspect of this study. There is a marked distinction in some discourses (B2, B3, B4 and B6) between the psychological expertise that is based on compassion and knowledge about the nature of intellectual disability and medical expertise that addresses the underlying organic deficit. Teachers are the ones who have psychological expertise but it is the therapist and the psychologists who have the authority to exercise the medicalised gaze and to understand the truth about intellectual disability, bolstered by the technologies of intelligence testing and therapeutic techniques. The teacher can address issues that arise in the social context, for example, bullying and an inappropriate curriculum. These are the domain of social aspects that create disability in the social model of disability (see chapter 2). Only the medical gaze has the power to pronounce upon and address the impairment itself.

The family and community are variously figured as central to education (B1) and potentially harmful in the absence of appropriate education (B2). I have argued above that the discourse of B6 is rooted to some extent in the context of limited resources. In this perspective, parents' major concern is with safety and freedom from abuse. The knowledge of parents is generally devalued relative to that of the experts, as noted in chapter 4.

Advocacy is an element of all discourses, except for B5 (which draws on a knowledge about the truth of intellectual disability as its ethical force). The discourse of B1 (and B3 to some extent) adopts a liberal humanist view of human rights as something that everybody is entitled to by virtue of their humanity (see chapter 2). These rights are limited to an educational context and access to appropriate educational provision in B2 and B4. In B6 these rights are limited to protection from abuse.

Quibell (2005) notes two types of rights discourse in her study of community care of intellectually disabled people in Australia. The first is what she terms a Formal-Rights discourse that makes claims to the official recognition of the individual’s rights, usually claims to services and resources in the context of intellectual disability. This type of discourse is in evidence in B2 and B4, where special needs constitute a right to special resources for education. The second type of rights discourse is that of Social-Progress, which makes a claim to social justice to be brought about in collective action. This is in line with the inclusive education approach of B1. Rights are seen in terms of equality and protection. B6 also makes a claim to human rights but this is a claim on negative rights, that is the freedom from abuse as opposed to the claim for the autonomy of B1.

Conclusion

In presenting the above Q-study I have identified accounts in educational discursive practices in Buffalo City. I have also made a comparison between these discourses within the themes used in the descriptions. The issues identified in this comparison draw on, and have implications for, the way in which the intellectually disabled person is represented as a subject for education. This will form the basis of the discussion in Chapter 8, in response to my third research question:

What are the effects of these discourses in constructing the intellectually disabled subject and associated educational practice?

CHAPTER 8: REPRESENTATIONS AND EDUCATIONAL PRACTICES OF INTELLECTUAL DISABILITY: AN INTERPRETATION OF THE FINDINGS

In chapters 6 and 7 the notion of educational practice as the application of neutral and evidence-based principles to address an identifiable organic deficit within certain individuals was destabilised. An examination of a range of discourses revealed multiple understandings of the problem of intellectual disability that enable certain educational practices with certain power effects and disallow others. In this chapter I relate discourses of representation to those of educational practice by considering conceptual and theoretical similarities between these two sets of discourses. The intent of this discussion is to address the research question:

3. What are the effects of these discourses [of representation and educational practice] in constructing the intellectually disabled subject and associated educational practice?

In order to understand the interaction between representation and educational practice, I shall begin the discussion by examining how power operates in special educational practices, through differentiation and exclusion under the authority of the medico-psychological gaze. It is argued that these practices are bolstered and packaged for deployment in a multitude of educational contexts through a form of psychological expertise that I term disability expertise in the study context. However, it is not only professional knowledge that informs educational practice. In the current context, the salience of a) religious accounts of disability and b) a concern with the rights of disabled people and c) the role of community and family have been noted. These strands are evident in educational practice and are discussed further below. The final section of this chapter entails a consideration of the ways in which constructions of impairment constrain and produce certain types of subjects within educational practice. Since I shall refer repeatedly to the accounts and discourses identified in chapters 6 and 7, I present a summary of these in Appendix K for ease of reference.

Professional knowledge and power

Disciplinary power is exercised through reference to the norm. The individual is ranked and given value within a comparative system thereby becoming the subject of their own ranking and the object of an overarching comparative system that marks the boundary between the normal and the pathological. The effect of discipline is to create docile bodies that are made productive at the same time as being deprived of political force (Foucault, 1975/1995). The outstanding features of power in the discourses identified in this study are exclusion and differentiation, each of which will be discussed below.

Exclusion

The roots of exclusion from education have been noted in chapter 4 as arising in the context of compulsory education. It was the pragmatic exclusion of problematic students from highly regulated classroom settings in the first place that necessitated the development of testing instruments to properly allocate individuals into special or regular education. Intelligence testing gave a scientific and ethical rationale to this exclusion, which both allowed the regular school system to be rid of troublesome individuals while at the same time setting the parameters for the educable subject. Thus, as noted by Hook (2007), it is not only those who fall foul of the measuring system that are disciplined but rather the control of these difficult individuals is deployed as a strategy to justify ever increasing controls and surveillance of the entire population.

Within the South African context I noted in chapter 4 the exclusion from education based on race. This past history makes of separation a “decadent and immoral” response to difference (van Rooyen & Le Grange, 2003, p. 11). Exclusion therefore requires a strong ethical motivation to cast aside this perspective in the South African context. There are three sources for this motivation apparent in the current study that inform dividing practices to distinguish the normal from the disabled, namely a) professional knowledge, b) provision of love and care, and c) protection from abuse.
I shall discuss each of these below.

Firstly, knowledge about the truth of disability casts exclusion in the best interests of the child. Professional knowledge about the nature of disability as an object in the world is evident in *A4.3: Medical model/religious discourse*. This discourse informs an educational perspective in which educational options should be decided upon by professionals in the child's best interests, notably *B5: Effective education must be tailored to the child's needs*, and *B2: Special needs require special provision*. Both of these discourses assume the existence of different types of children who will require different forms of education and both endorse the validity of professional knowledge in determining who belongs in which category, and who will be included or excluded.

Secondly, exclusion is a product of the Christian morality of care, love and duty (*A4.3: Medical model/religious discourse,* and *A4.4: Community/religious discourse*). This plays out in educational discourses that prize the love and compassion of teachers located in special schools (*B2: Special needs require special provision, B3: Inclusive education is a dream of the future* and *B6: Special education keeps children safe*). Intellectual disability imposes a duty of care and protection on the education system that is only taken up fully in special schools. This will be further discussed in the section on religious discourse below.

A third impetus for exclusion is the vulnerability of the intellectually disabled child who must be kept out of harm's way in separate provision (*A4.3: Medical model/religious discourse*, see especially the accounts of *A1.2: A person dependent on their family, A3.5: A person with a condition that is an object of expert knowledge* and *A2.3: A difficult challenge to their family*). The concomitant educational practice is most clearly expressed by *B6: Special education keeps children safe*, but also to some extent in *B2: Special needs require special provision*, where safety of children is a key feature in the consideration of educational provision.

Disability continues to be a force for exclusion in the current context despite inclusive rhetoric. While exclusion on the base of gender or race is abhorrent in the South African situation, exclusion of disabled people is based on a scientific knowledge, their special needs for care and their extreme vulnerability. These justifications obscure the power effects of exclusion and construct it as a disciplinary or ethical matter rather than a potentially political one. The human rights discourse of *B1: Inclusion as a human right*, which will be discussed further below, roundly rejects this perspective.

Differentiation

The practice of differentiation has expanded from the gross distinction between normal and pathological to much finer within-category distinctions, as has been discussed in chapters 3 and 4. The effects of differentiation are to individualise the subject within a globalising system in such a way that they become visible, given their location within a grid of description. The intellectually disabled learner is described in detail through the application of disciplinary technologies of intelligence tests, assessment and expert knowledge. This study reflects the existence of both a) gross distinctions between the normal and the abnormal as in *B2: Special needs require special provision* and *B6: Special education keeps children safe* and b) much finer distinctions, with *B5: Effective education must be tailored the child's needs* being the most highly differentiated discourse.

The special educational discourse of *B6: Special education keeps children safe* rejects graded practices of differentiation beyond that between the "normal" and the "disabled" in that all children, no matter the severity of their disability, should be able to be admitted to special schools. The category of "disabled" is thus relatively homogeneous, defined by the need for love and care. In this sense a stereotype of intellectual disability is created. The account of *A1.6: A stereotyped person,* can be viewed as one of resistance to this stereotypical view of the dependent, vulnerable intellectually disabled person. This account (A1.6: *A stereotyped person*) expresses frustration with the generally low expectations of intellectually disabled people.

In the discourse of *B5: Effective education must be tailored to the child's needs*, grades of severity are minutely separated from each other since individuals are deemed to require different educational practices. This discourse apportions exclusion and inclusion conditional on factors, predominantly *internal* and *inherent* in the child, most prominent of which is the level of severity of the disability. If this professional knowledge is not brought to bear on the problem of the correct placement of individuals, there is a possibility of harm resulting. As one respondent loading onto

B5: Effective education must be tailored to the child's needs, puts it: *"In the ex-white department, we had school psychologists who would pick up [mild to moderate intellectual disability] through IQ tests then move kids into special class. Those kids did not come to our school. In the black and coloured schools, they were not picked up earlier. They did not have special classes so they came to our school. The behavioural problems come from kids who should not be here"* (Q-study B, S57: +4, P6). In this view, an incorrect assessment of the child's inherent potential results in behaviour problems that then disrupt the education of those who are correctly placed according to their potential. The damage that incorrect placements do is a danger evident in the discussion of mainstreaming in chapter 4 and most clearly expressed by Alston (2006) where the inclusion of intellectually disabled children is set against the burden that they will place on an already diverse system. Thus, within the differentiated discourse of B5*: Effective education must be tailored to the child's needs* presented here, it is in everybody's best interests that only children with mild intellectual impairment that should be given access to the mainstream.

The practice of special education can be viewed as a project of "disciplining difference" (Rose, 1998a, p. 104). The skills that are measured through professional technologies form a grid that serves to make the individual difference with respect to intelligence and social adaptation, visible and comparable to the norm. The effect of this is to stabilise difference and make it orderly within a perceptual frame (Rose, 1998a). In the case of intellectual disability in South Africa placement options for schooling are determined by practices of differentiation.

Prior to the introduction of inclusive education policy, school placement was determined by degrees of severity with a heavy dependence on IQ scores (see chapter 4). The National Strategy for Screening, Identification, Assessment and Support (Department of Education, 2008) outlines the move from differentiation according to disability/severity to a more subtle form of differentiation according to levels of support needs as demanded by Education White Paper 6 (Department of Education, 2001). This differentiation of support needs draws on regular teachers' knowledge up to a point but this is exercised under the supervision of the medico-psychological gaze discussed below.

The Medico-psychological Gaze

In the early problematisation of intellectual disability, as described in chapter 3, the medical profession held the authority to classify, based on physical judgements. Subsequently, the intelligence test presented a victory for Psychology in gaining the power to pronounce upon intelligence and its lack (see chapter 4). Doctors and psychologists (and to some extent, therapists) are given the authority to exercise the medico-psychological gaze that is rooted in the claims to truth of expert knowledge that makes the body (or the mind) visible so that what was already there, waiting to be revealed, is brought into the light of truth (Foucault, 1963/2003). The mastery of diagnostic techniques allows them to make visible and pronounce on the specific individual's condition relative to the norm and to prescribe a course of action. In the case of special education, lesser authorities (teachers, nurses and parents) are bound to accept privileged professional knowledge (Howell, 2006) and comply with the prescriptions made.

In the discussion of discourses presented in chapter 7, I noted how some educational discourses distinguish between a) the knowledge of teachers and b) that of therapists, doctors and psychologists. The medico-psychological authority of the latter group grants them powers to pronounce upon the organic deficit (impairment) itself. This power is not granted to teachers, who are more likely to possess psychological, or in this study *disability,* expertise, if they have the necessary guidance of the authorities on the truth of intellectual disability. The medico-psychological gaze is directed at impairment itself, as the organic element of the disability/impairment binary. The disability pole of the binary is the target of disability expertise, which will be discussed further below. The adoption of a positivist scientific method in special education with its claim to objective knowledge establishes special educational techniques as a superior form of knowledge, able to exercise the medico-psychological gaze, that dominates that of parents, disabled people and regular teachers within special education practice (Connor, 2005).

In the account of A3.5*: A Person with a condition that is an object of expert knowledge*, professional knowledge that makes the impairment visible is highly valued as the truth about intellectual disability. The truth must be communicated to parents and to communities in the best interests of the child and to minimise abuse. The educational practice of *B2: Special needs require special provision* relates strongly to this conception. The true needs of the child, made visible by the competent authorities, must determine educational provision. It is this match that constitutes a fair and just treatment of the intellectually disabled child. Should these true needs be ignored, there will be a violation of rights. In the discourse of *B4: Excellent special education as a right*, such is the faith in professional knowledge that it is invoked, at whatever expense, to address and change organic deficit to the point where the disabled child can do what the normal child can. These discourses prize technical skill and diagnostic mastery that can address the very real impairment, the organic deficit of the individual body. This is in contrast to (but sometimes in combination with) the concept of psychological expertise as a more malleable and diffuse concept that is directed toward the *effects* of impairment, that is, the disability.

Disability Expertise

Rose (1998a) notes the flexibility of psychology as a discipline that lends itself freely to those professions that deal with human conduct in all its troubling diversity and pathology. Doctors, nurses, therapists and special education practitioners can draw on an expertise that "refer(s) to a particular kind of social *authority,* characteristically deployed around *problems*, exercising a certain *diagnostic* gaze, grounded in a claim to *truth,* asserting technical *efficacy*, and avowing *humane* ethical virtues" (p. 86). I shall argue that special educators apply this form of expertise in particular ways and I shall use the term "disability expertise" in my discussion. As a form of psychological expertise, it draws on the language and ideas of psychology, since "It appears as if it [psychology] can systematize and lend coherence to the ways in which authorities visualize, evaluate and diagnose the conduct of their subject – render rational the grounds of decision and action" (Rose, 1998a, p. 87). Safely located within this legitimate psychological frame, disability expertise gathers an ethical and moral force, based on scientific knowledge of the truth of disability.

In the discourses that prize the special education enterprise (*B2: Special needs require special provision, B4: Excellent special education as a human right, B5: Effective education must be tailored to the child's needs* and *B6: Special education keeps children safe*), professional expertise consists of a) mastery of diagnostic technique, b) knowledge of disability, and c) understanding of disabled children and love and compassion for them. Mastery of diagnostic technique can be distinguished in the current discourses as being incorporated within the medico-psychological gaze. This is the power to make the impairment visible and definable. The knowledge of disability takes different forms for the medico-psychological gaze and for disability expertise. For the medico-psychological gaze, disability knowledge is based on a scientific knowledge of the truth of intellectual disability. As a component of disability expertise, knowledge appears to be more a familiarity with "the disabled", their nature, their habits and their needs. This form of disability knowledge is not about making the impairment visible but rather about understanding the disabled in ways which are, in many respects, pre-defined by the medico-psychological gaze.

To some extent this form of disability knowledge encapsulated in disability expertise is code for an absence of ill treatment and abuse, see for example *B6: Special education keeps children safe*. Where disability expertise is absent, it will not be safe for disabled children. However, this is not an expertise that can be easily claimed. It requires supervision and sanction. For example, within the discourse of *B2: Special needs require special provision* and *B4: Excellent special education as a right*, understanding and compassion are important, but this is not an ordinary compassion since it is lacking in those who do not practice under the auspices of a medico-psychological authority. Only those who have had special training or the experience of working in a special school can lay claim to this authority. The professional practice of the regular teacher does not include disability expertise and these teachers are disqualified from educating disabled learners unless they receive the required training.

There is some debate as to whether disability expertise can only be found in special schools (*B2: Special needs require special provision* and *B4: Excellent special education as a right*) or in regular schools too (*B3: Inclusive education is a dream of the future*). B3*: Inclusive education is a dream of the future* is of interest in that it suggests that diagnostic mastery that makes impairment visible (the medico-psychological gaze) is required for the treatment of severe disability and can be distinguished from softer skills directed at mild disability (disability expertise). The medico-psychological expertise is properly located within special schools, whereas disability expertise could possibly be found in regular schools as well. The human rights discourse of *B1: Inclusion as a human right*, on the other hand, rejects any form of disability expertise and elevates the professional knowledge (perhaps a form of educational expertise) of the regular teacher to the level where it is adequate for all children.

These configurations of expertise suggest the arrangement of impairment and disability in the following series of interlocking concepts:
The *impairment* elicits the medico-psychological gaze that can be exercised by the therapist/doctor/psychologist. These authorities possess scientific knowledge and a special diagnostic ability to classify the mind and body of the educational subject. In so doing, they set the limits of possibility and fix impairment as a static entity (sometimes with a number, such as IQ attached), a property of the individual, and on this basis they prescribe valid disciplinary responses to impairment. Their presence is most required where the level of impairment is severe and their skills are most likely to be deployed in specialised or pivotal decision-making settings.

The *disability* calls for disability expertise, especially familiarity with disability, understanding, love and compassion. Disability expertise is distinct from other forms of educational expertise since it is an intermediary for, and practiced under, the medico-psychological authority. Teachers in regular schools (*B5: Effective education must be tailored to the child's needs*), parents (*A4.3: Medical model/ religious discourse*) and teachers in special schools (*B5: Effective education must be tailored to the child's needs*) must be educated about disability. If they are suitably educated then they can carry out the prescriptions of the medical/psychological authorities.

Disability expertise, as discussed above, is easily aligned with a representation of intellectually disabled people as vulnerable due to their organic deficit (requiring care and protection) within a religious frame as evidenced in *A4.3: Medical model/religious discourse*. A convergence of old (Christian) and new (disciplinary) forms of pastoral power (Foucault, 1979) places the special educator as the leader of the flock, an intermediary of the superior power of the medico-psychological complex, imbued with the moral force of Christian compassion. As such he or she is accountable for the flock, knowing each one in detail through observation and assessment (Hook, 2007).

In conclusion of this section on power and the practice of special education, it is my contention, based on the discourses examined in this study, that practices of exclusion and differentiation in education construct intellectual disability in schools as an individual organic deficit. The best interests of the child with the deficit are deemed to be served through the technology at the disposal of the medical/psychological authorities. The techniques and practices of these authorities are infused throughout the education system by means of the application of psychological expertise in a specifically disability related form. Disability expertise is a scarce resource that can only be found in certain places and under certain authorities, necessitating careful placement of individuals. The pervasiveness of disability expertise in educational discourse for intellectually disabled people undermines the intent of inclusive education since it remains under the jurisdiction of the medico-psychological complex and outside of the practice of regular teachers.

In the context of this study, disability expertise has strong religious underpinnings. The moral force of acting in the child’s best interests, with knowledge, understanding and compassion is bolstered by Christian ethics and will be discussed further below.

Religious Discourse

It is useful to explore the religious dimension of disability further because of its centrality in the current study. Stiker (2002) notes the association of disability with sin in the Judaeo-Christian tradition. In the Old Testament, disability belongs in the world of the profane and is excluded from the sacred because of its contamination with sin and the impurity that it represents. However, he argues, it is this very religious exclusion that placed an ethical and social responsibility on the faithful such that “the non-integration of the disabled in religious practice is their precondition of their non-exclusion from the culture” (p. 31). He portrays the Old Testament view of disability as promoting social inclusion although requiring exclusion from the sacred.

The practice of Jesus in healing and relief of disability disrupts this arrangement between religious interdiction and social integration. The prohibition of the disabled from the sacred is shattered as the marginalised are presented as closer to God and most loved by Jesus. Impurity is not to be found in the mark of disability, rather impurity lies in the behaviour of one towards other human beings: “Only one thing is sacred, and that is human fellowship, which can be profaned by lack of respect, lack of love, lack of *agape*” (Stiker, 2002, p. 34). The integration of the disabled person becomes wholly a matter of ethics and individual conscience as a matter of charity.

In terms of representational work, this figures the intellectually disabled person as one who is most deserving of compassion and belonging in the church but is not always accorded these rights. The disabled person, therefore, needs special intervention. In terms of education, a charitable mode of functioning is called upon. The education of intellectually disabled people is not a technical task but rather a Christian duty of love. Those who teach intellectually disabled people demonstrate this love and require support from the community as an expression of the community’s Christian values.

The medical model is aligned with religious discourses in A4.3*: Medical model/religious discourse* in such a way that the intellectually disabled person is figured as an innocent requiring special care within a religious, charitable value system. The impairment requires specialised treatment and expertise to maximise potential but this expertise cannot overcome the impairment. at this point religious values of care and protection will be called upon. This resonates with the educational discourses of *B2: Special needs require special provision* and *B6: Special education keeps children safe* that foreground the vulnerability and need for protection in educational practice. Thus it is the love, compassion and understanding that are valued in special schools as equal to, or above, technical skills within these discourses. The innocence of the intellectually disabled person invokes a religious duty of compassion, care and protection. While the person can learn to some extent, this is constrained by the impairment and education can only be effective up to a point where a charitable response of care and protection would then need to be instigated.

According to Stiker (2002), the mysticism of the Catholic church, as embodied in the life of St. Francis of Assisi, elevates the marginalised and the disabled *above* others. They are more blessed, and closer to God than the unafflicted. Instead of being cared for, they were now glorified and “marginality [became] accepted as a positive value” (Stiker, 2002, p. 83). This mysticism is evident in the account of *A2.6: A blessing and a gift from God* (and to some extent in *A2.2: An innocent and vulnerable child of God*) that sees disability as a blessing and is only adopted by parents. It is a highly positive account that draws on spirituality as a central feature. It poses a different way of understanding intellectual disability as a religious symbol.

The participant comments (see chapter 6) support the contention that the representations of intellectual disability are saturated with Christian morality in that a) Christian values relate to the acceptance of disability, and b) explanation of the cause is offered by reference to Christian belief. I shall discuss each of these further below.

In some accounts the church is viewed as a haven of acceptance for intellectually disabled people. For example, within the account *A1.2A: A vulnerable person*, it is a place where intellectually disabled people can be themselves without feeling the pressure to hide their disability. On the other hand, the church is also seen as a culprit of the same discrimination that is experienced by intellectually disabled people in the community at large (*A2.2: An innocent and vulnerable child of God* and *A3.1: A person to be understood and advocated for by professionals*). Overall, the expectation is that the church should be a welcoming place and this is not always borne out by the experience of parents and adults with intellectual disability. There are indications in the literature that religious beliefs do not necessarily translate into a broad acceptance of disability (McNair, 2007; Selway & Ashman, 1998). The account of *A3.1: A person to be understood and advocated for by professionals* is particularly interesting in that the professional takes on the role of caring, is figured as being neglected by conventional religion. This suggests the direct assumption of the pastoral role by the helping professions in an exercise of pastoral power.

Religious explanations are also given for the cause of disability. Hlongwana and Mkhize (2007) note in their study of Christian values within an HIV/ AIDS support group in South Africa that religious values are used to explain the cause of

HIV/AIDS as either a blessing or a curse. In terms of intellectual disability, the blessing concept is evident where the child is seen as a gift from God. Two of the factors in the parents Q-study (*A2.2: An innocent and vulnerable child of God* and *A2.6: A blessing and a gift from God*) endorse this sentiment and construe it as a blessing either because it builds their relationship with God through being tested or because it enriches their lives on a daily basis. The account of *A2.3: A difficult challenge to their family* is more ambivalent since the burden that God imposes is not seen necessarily as a punishment but certainly as a challenge. However, this challenge is positive to the extent that it serves to strengthen the carer's relationship to God. Contained within this concept of the 'gift' is the sense of being chosen to bear this burden. This element of being chosen is also evident in the HIV/AIDS literature (Hlongwana & Mkhize, 2007).

While the view of disability as punishment does not emerge in the current study, it is worth noting that it is reported in other studies in the Eastern Cape. Gara (2007) presents accounts of rural mothers of disabled children who highlight the rejection that they experienced from their families and partners on the birth of a disabled child. They were viewed as being to blame, either through not taking care of themselves or through some transgression of a moral or cultural code of conduct.

In a study in the Western Cape some parents saw disability as punishment but others saw themselves as being chosen to face the challenge of an intellectually disabled child. God is also called upon to heal and make it better (Masasa, Irwin-Carruthers, & Faure, 2005). In terms of education, views taken on the cause of disability can affect the course of action to be taken. If it is "the will of God" there could be a tendency to focus on the fulfilment of one's own duty as a parent or professional rather than the development of the intellectually disabled person as a human being in their own right. Where the child is seen as a punishment, this is even more problematic as the child can be hidden away and viewed with shame (Gara, 2007).

The association between discourses of representation and educational practice has revealed an interesting aspect of the medical model within the local context. In representational discourse, the thread of Christianity is quite marked. In educational practice the overt Christian reference is absent. However, it is my contention that the notions of caring, compassion and love are proxies for Christian values in educational practice. These religious values contrast with, but also draw on, the more secular human rights approaches, which are discussed below.

Rights and Intellectual Disability

Human rights concern the individual freedoms that every person should have by virtue of being human (see discussion in chapter 2). In this discussion, I examine the way in which rights underpin the human rights discourses of *A4.2: Social model/human rights discourse* and *B1: Inclusion as a human right*. I then examine the limited rights perspectives evident in the discourse of *B5: Effective education must be tailored to the child's needs* and finally the right to protection from harm as expressed in *B6: Special education keeps children safe*.

Human Rights

Within the discourse of *A4.2: Social model/human rights discourse*, an overtly political stance is adopted, one of advocacy for those who cannot speak for themselves, given their marginalised position. Within this frame, the intellectually disabled person is viewed as a victim of social injustice who is deprived of his or her autonomy and basic human rights through the attribution of incompetence based on organic defect. There is a battle to be fought for the recognition of individual autonomy and the right to make choices for oneself. This discourse is strongly linked to the social model of disability and adopts an unconditional view of human rights as being accorded to every person by virtue of their humanity. Independence and autonomy are valued very highly. Practices of care are treated with great suspicion, as they are seen as pretexts for the erosion of autonomy.

This perspective is evident in the educational discourse of *B1: Inclusion as a human right* and sits squarely with an orthodox inclusive education position based on the social model of disability. Since it is the environment, and not the disabled person, that must change, curriculum becomes the site where the problem of intellectual disability is addressed. This constructs inclusive education as follows:

1. All children come to school with diverse needs and thus there are no essentially distinct groups of children.
2. General education is responsible for the education of all children.

3. A flexible curriculum and trained teachers are essential to an effective response.
4. The success of inclusive education is measured by the extent to which societal change occurs to enable all citizens to participate fully in community life (Peters, 2007).

This position specifically undermines the special education enterprise. It equates disability with diversity and recognises that the regular classroom is a place where diversity must be addressed. Further, disability expertise is not a requirement. Rather general teaching expertise is needed, thus loosening the grip of the medico-psychological authorities. The view of human rights expressed here can be related to the Social-Progress discourse described by Quibell (2005) in her Australian study as one that:

> constructs intellectual disability as at least in part shaped by their environments and the attitudes of others. Inclusive attitudes and environments are practices advocated in this discourse to bring about social change for people with intellectual disabilities. (p. 230)

As noted in chapter 2, the rights based imperative to full participation poses a dilemma for activists for intellectually disabled people, as agency and autonomy are central to the exercise of rights. This dilemma is predicated on the degree to which care and support can be balanced with autonomy. To what extent can full autonomy be in the best interests of the intellectually disabled person? Do the rights to protection and care limit their right to autonomy? The limited rights perspective views the best interest of the child as a legitimate guide to drawing the line between autonomy and protection.

Limited Rights

For *B2: Special needs require special provision* the rights of the intellectually disabled person are best served through the adequate provision of specialised services and treatment. Inclusion in society is viewed as dangerous and filled with potential for abuse. Education does not have an answer for the problem of society as a whole and can only ensure protection and skills development at school. As such education is restricted to the present with little preparation for employment and community life, a legacy that can perhaps be linked to the notions of ongoing care and support requirements (McConkey, 1998; van Rooyen, Newmark, & Le Grange, 2003). The child's best interests are a salient feature of this account. It is apparent that these interests are best identified through professionals who know about intellectual disability. After school, they will still face an uncaring community and further protective institutions will be required. What is demanded here is the right to appropriate services.

The discourse of *B6: Special education keeps children safe* is vociferous in its demand for protection from abuse of intellectually disabled children. In this sense it is a right to freedom from harm that is advocated for. The community is hostile and the rights of families and children with intellectual disability must be asserted in the face of this. This is not so much a right to participation (*B1: Inclusion as a human right*) or to services (*B2: Special needs require special provision* and *B4: Excellent special education as a right*) but a right to protection. As such it is similar to (but not identical with) the Formal-Rights discourse noted by Quibell (2005) as a discourse that "emphasises fixing problems of discrimination and exclusion through the enforcement of the formal legal rights of individuals with intellectual disabilities" (p. 230). It is here that the harsh realities of intellectual disability in everyday life, especially in situations of poverty is brought to light in educational discourse. These harsh conditions relate to poverty and unemployment (Emerson, 2007; Erevelles, 2002; McKenzie, 2007), physical, sexual and emotional abuse (Groce & Trasi, 2004; McConkey & Smyth, 2003) and general exclusion from participation in community life. In this configuration, the community is seen as a hostile place that, far from being a resource for overcoming barriers to learning as suggested by Education White Paper 6 (Department of Education, 2001), is a danger from which intellectually disabled people need to be protected.

These protective, special education discourses are largely absent from inclusive education policy debate. This is expressed in one particular comment from a participant loading onto B6: *Special education keeps children safe*: *"To my side, I don't agree when we go to meetings and they say that we must be in inclusive education. It depends on these children and how you feel yourself. I for one do not want him there because he has not got care there. It can work if they have a disabled in the class from before - not just started now. They are not going to write and read*

like others. Even I cannot understand him. If he wants to go to the toilet with 40 learners in the classroom, how will he communicate" (Q-study B, comment, P8).
The frustration with the advocacy for inclusion and the harsh realities of a regular classroom are evident. How can this discourse be understood? It constitutes a discourse that is directly at odds with and in fact resists an inclusive education and training system. This stubborn resistance is construed in a certain way within Education White Paper 6. Van Rooyen, Newark and Le Grange (2003) note that within a systems discourse of Education White Paper 6, parents are constructed as "those who need to be persuaded not to keep disabled children in 'dark bedrooms and sheds'" (p. 175) and who constitute barriers to learning in themselves through their lack of recognition and involvement with their children. They are a problem to be dealt with through the application of information and advocacy campaigns: "The home here is constituted as a place of isolation and imprisonment, not of possible learning. Parents are constructed as imprisoners, unwilling to see their wrong: they need to be convinced. They are constructed as stubborn" (van Rooyen, et al., 2003, p. 176).

As such, a care and protection discourse is relegated to the margins as well as the voices of parents who feel that their children will not receive the resources, care and protection that they require in a regular school. Parents are often viewed as "overprotective" by professionals in their attempt to balance care and protection with exposure to learning and social experiences (McConkey & Smyth, 2003). Given the construction of parents noted above, there is no basis for dialogue around the concerns that prevent parents from embracing inclusion. These issues are quite clear from the discourse of *B6: Special education keeps children safe* and concern large class sizes, inadequate resources, untrained teachers and most significantly a deep concern for the safety and happiness of their children. These concerns are neglected and the "problem of parents" is addressed rather by giving information to ignorant, stubborn parents (van Rooyen, et al., 2003).

A different view emerges if one listens to the stories told by parents with regard to their experiences of accessing education for their children. Gara (2007) describes the burden of mothering a disabled child in settings of poverty. The lack of support that these mothers experience from the family and the community engenders a protective reaction:

> Nozuko seemed to be frustrated about her child who was abused by other children in her neighbourhood. She related how difficult it was for a child to tolerate teasing by other children. She emphasised how emotionally demanding it was to fight for her child:
>
> > "Pumezo used to cry when playing with others, I became so worried because they are taking the chance of his disability. (Raising her voice) You must love your baby; you must protect him from being abused by others." (Nozuko, 17.07.2006). (Gara, 2007, p. 37)

Similarly, McKenzie and Loebenstein (2006) describe the difficulties that parents experience in gaining admission for their disabled child into the mainstream where the policy implications of Education White Paper 6 have not yet become a reality. The extra effort required by parents to maintain their disabled child in a regular school is noted in a South African context, indicating that it takes time to develop partnerships (Engelbrecht, Oswald, Swart, Kitching, & Eloff, 2005). In the absence of such partnerships and the support required to develop and maintain them, the special school is constructed as a haven of safety in the discourse of B6: *Special education keeps children safe*.

The rights of the intellectually disabled person coalesce around two poles – that of autonomy and agency at one end, and that of protection and care at other. The human rights perspective is located on the autonomy end of the spectrum and the limited rights fall closer to the protection and care pole. Alternative understandings of the balance between autonomy and care can be found in the discourses of *A4.1: Interactive discourse* and *A4.4: Community/religious discourse.* These discourses have implications for the location of the intellectually disabled person within the community and the family, drawing on community resources.

Family and Community

To understand the significance of an interactive understanding of intellectual disability, I draw on feminist disability studies, specifically as regards the ethics of care. This line of research arose from critiques of feminist research examining carers and 'dependents' in situations where people have to rely on families in order to complete their daily tasks. Morris (2001) noted that a distinction was made between two groups of women, the carers and their dependents, and that the latter were made invisible. They were not included in a feminist analysis of women's experiences. The person who was cared for was classed as having needs and carers met these needs. In this configuration need became a property of the disabled person. Thus, feminist theorising of care focused on the naturalisation of care as women's work, thereby leading to exploitation of women.

The social model of disability, in contrast to feminist research, minimises individual needs and the private space, emphasising the independence of the disabled person once barriers have been removed. Within this frame care is seen to be disempowering, casting the disabled person in a passive dependent role and as a burden to the carer who is seen as brave and self-sacrificing (Watson, McKie, Hughes, Hopkins, & Gregory, 2004). Neither of these perspectives account for scenarios of ongoing care, such as arise in the case of intellectually disabled people, particularly those who live in conditions containing multiple and diverse barriers.

Morris (2001) argues for a new ethic that allows for the acknowledgment of the equal human value of the carer and the dependent. The tension between independence and needing help has broadened the feminist ethics of care and has led to the exploration of interdependence. This explores the ways in which we depend on each other through processes of reciprocity and assumes that there is always value in relationship no matter how one-sided it might look on first consideration (Rohrer, 2005).

The interactive discourse of A4.1 poses an avenue for exploration of the caring relationship. It was noted as being a non-professional discourse that was associated with intellectually disabled adults. It places the intellectually disabled person in ongoing interaction with others, requiring and contributing more or less support in different situations. Competence is not an individual property but is distributed between individuals depending on the context. In this perspective care is not something that is required all the time and in all situations. The need for care or support fluctuates as it does for all human beings regardless of disability, but forms of support might differ.

As such interdependence is valued more highly than independence and constitutes a process in which giving and taking care becomes an unexceptional part of daily life:

> The relational qualities of interdependency draw attention to the mutual needs embodied in caring activities and caring responsibilities. ….it [is] likely that all people will need help, support and care of different kinds at different points of the lifecourse. (Watson, et al., 2004, p. 345)

In this account of interdependency both carer and cared for are visible in flexible, mutual relationships in which the practice of care shifts over time and across situations. Care is no longer a burden but rather a social relationship. The notion of human rights is less significant for this understanding than that of human relationships with a fluid understanding of competence as constructed in relationship.

My examination of educational discourse suggests that the inclusive education discourse of *B1: Inclusion as a human right* is most closely related to a fluid understanding of competence. The principle of curriculum adaptation creates possibilities for finding contexts where competence can be displayed. However, I would suggest that the interactive discourse of A4.1 goes further than B1: *Inclusion as a human right* in suggesting that the impairment itself is amenable to social interaction. This will be discussed further in the section on the construction of impairment.

Unlike the interactive discourse, the community/religious discourse of A4.4 locates the impairment/need within the individual but the incompetence that results from impairment is not seen as an impediment to social inclusion. It only becomes a barrier to inclusion where the community itself is incompetent in dealing with disability. The intellectually disabled person can fill a number of societal roles but this will not be in the same way as normal people. It can only be achieved within the constraints of organic deficit.

It is interesting to note that the participants that load onto this factor in the professional and parent Q-studies are all black. Without labouring the point beyond what it can bear, it offers a basis for reflection on different senses of community between racial groups in South Africa. Caring is figured as a community obligation. Interdependence exists because the community is made up of its members and will only be in a state of health where it can cater for these members. The strong emphasis on community responsibility evokes the concept of *ubuntu*, as expressed in "an African proverb '*Umuntu ngumuntu ngabantu'* meaning 'a person is a person through other persons. (Shutte, 1993, cited in Lorenzo, 2003, p.760)

Values of the community as a whole mean that the person who is different, because they are less competent in particular domains, does not forfeit his or her place in the community. With this strong sense of belonging, there is minimal requirement for individual competence or autonomy. At the same time, the community needs to be educated, to be made aware and to develop its competence in dealing with intellectual disability.

Lorenzo (2003) highlights the operation of concepts of *ubuntu* in a group of disabled women in the Western Cape:

> Practitioners working in the disabilityfield need to re -examine the goal of independence in rehabilitation process in the light of the philosophy and values of *Ubuntu*, which seeks to cultivate a spirit of interdependence based on an improved self-image. It is this interdependence in meeting physical, emotional and spiritual needs as a means of human development that the women have spoken of so strongly as the foundation to social and economic development. (p. 774)

This scepticism of goals of independence (that are so central to the human rights as autonomy discourse) directs attention toward community and group processes. The adoption of a community competence or *ubuntu* aligned discourse lays an emphasis on interdependence and the holistic incorporation of the individual into the collective. Individual competence is important insofar as it builds community.

A connection of the community discourse to education could also be made through further examination of B3 - (the polar opposite to B3: *Inclusive education is a dream of the future* and a discourse that emphasises the impact of poverty and community on educational provision) that I have left under-described due to my reservations about its validity. If it could be shown to be valid, it would present intriguing possibilities for a community understanding of disability that integrates issues of poverty with those of disability. The problem of intellectual disability would thereby be reconfigured as a social problem amenable to political action aimed at eradicating poverty.

The Construction of Impairment and Disability

I have noted in chapter 2 that the social model account of an impairment/disability binary is problematic in that impairment is under-theorised and becomes a problem to be addressed through positivist medico-psychological knowledge. The existence of impairment as a fixed organic entity is evident in all but one discourse (*A4.1: Interactive discourse*) of representation but the extent of its effects on resulting disability varies considerably across discourses.

The human rights discourses of *A4.2: Social model/human rights discourse* and *B1: Inclusion as a human right* emphasise social processes as constructive of disability. Impairment is fixed but disability is dynamic within social contexts. It appears that the impairment is an organic entity, which has the *possibility* of restricting function. Impairment is delinked from possibilities of autonomy and agency, which remain the concern of disablement in society. The social model in this respect does not *draw a line* as to where improvement is no longer possible by virtue of organic deficit. As such the monolithic nature of impairment begins to crumble ever so slightly. Disability is created by lack of opportunity and stigmatising practices. The educational practices within a human rights agenda minimise the relevance of impairment and reject practices of differentiation on the basis of impairment (i.e. severity). The problem of education of the intellectually disabled person is located within the curriculum and the educational system as a whole. Educational failure is reconfigured as a consequence of barriers that restrict access and participation. The rationale for education is full participation and human rights in society. This overtly individualistic view of human rights as belonging to the individual rather than the community might clash with more community orientated perspectives, such as that of *ubuntu* discussed in the community discourse.

The protective/religious/medical discourses of *A4.3: Medical model/religious discourse, B2: Special needs require special provision, B4: Excellent special education as a right* and *B6: Special education keeps children safe* verge on biologically determinist accounts that attribute the social condition of disability to the severity of impairment. Disability remains a static entity that requires special intervention rather than social change. The educational discourse of *B5: Effective* *education must be tailored to the child's needs* figures impairment as a static entity that can be obscured or exacerbated by community and family conditions. It can also have differential effects depending on severity.

As noted above, impairment falls under the medico-psychological gaze. In this light impairment/disease inhabits and is completely bounded by the individual body: "For us, the human body defines, by natural right, the space of origin and of distribution of disease" (Foucault, 1963/2003, p. 1). Impairment is an individual issue. The interactive discourse of A4.1 presents an alternative to these views of impairment that is worth exploring further.

The discourse of *A4.1: Interactive discourse* rejects the need to address impairment as a prerequisite for a normal life. It focuses rather on support and the distributed competence of people in communities who rely on each other in living together. Impairment is not a pre-existing object of knowledge but rather a dimension of the range of diversity that shapes, and is shaped by, social interaction. Competence can be developed in social interaction and the limits of organic impairment are not fixed nor do they constrain the ultimate outcomes. Competence is a continuously developing attribute that opens new horizons for participation, and develops through social inclusion. Autonomy is not valued highly as competence is a work in progress, and complete autonomy is unlikely to be achieved by any one regardless of whether they are disabled or not. For an interactive discourse, difference is a plastic property that changes with societal interaction as well as individual effort. The difference (impairment) itself is relatively fluid depending on the context.

Subjectivity

As noted in chapter 2, the individual is made governable through processes of differentiation under the medical gaze and the application of the norm. The question then arises as to what forms of subjectivity for intellectually disabled people are constructed in the discourses of the current study. In my discussion on subjectivity I note that this is in itself a contested term that is debated and theorised in multiple ways in the literature. For the purposes of this discussion, I view subjectivity as "that which ties the individual to himself [sic] and submits him to others in this way" (Foucault, 1982, p. 781).

The medicalised discourse of *A4.3: Medical model/religious discourse* with its religious overtones constructs a highly restricted subjectivity as an object of disciplinary and pastoral power. This is reflected in educational practices *(B2: Special needs require special provision, B4: Excellent special education as a right, B5; Effective education must be tailored to the child's needs* and *B6: Special education keeps children safe*) that place organic deficit at the centre of concern. The operation of an individualising technology that identifies impairment and the ranking of the individual within the grading systems of intelligence tests, educational tests and so forth allows for the exercise of a bio-power that has an anatamo-political application and enables a statistical comparison with the population. The lack of normality is a taken-for-granted fact, a problem within certain individuals that defines them totally. The intellectually disabled person is wholly and entirely encompassed by the disability, and the only dimension of diversity within the category is between levels of severity. In this sense disciplinary technologies have been effective in rendering the individual entirely visible and calculable. There is nothing there but what has been revealed through reference to the norm. Within this, there is a cross-referencing of incompetence with vulnerability – having rendered intellectually disabled people outside of the norm, it is now ethical and humane to protect them, not only from others, but also from themselves in their own best interests. The moral force of this imperative draws on a Christian ethic of love and charity.

The human rights discourse described above resists this total subjection and makes a claim for autonomy and self-representation as ways to reduce vulnerability and therefore to reduce the need for protection. The discourses of *A4.2: Social model/human rights discourse* and *B1: Inclusion as a human right* resist disciplinary power and construct a rational, individual and autonomous subjectivity (see chapter 2). Educational practice is directed at the development of autonomy within the individual, regardless of severity of impairment. However, as Erevelles (2002) argues, it is precisely this humanist subject that constitutes the intellectually disabled person as the irrational other. Resistance is framed in those terms that create otherness in the first place such that "the very ideologies that masqueraded as the salvation of these individuals were instrumental in relocating them to the very margins from which they had sought to escape" (Erevelles, 2005, p. 61). She warns, though, against a discursive theory of subjectivity that fails to address the dismal life circumstances, poverty and abuse that many disabled people have to endure.

Within account *A4.1: Interactive discourse* disabled subjectivity is loosely constructed as an ongoing project and part of the fabric of a larger process of attaining competence and social inclusion within a community. The factors that load onto this second order factor are *A1.1: A competent person, A1.4: An (ir)responsible person* and *A2.5: A person to be understood by the community*. These factors have in common the acceptance of the right to community participation in a range of contexts. The consideration of impairment refers rather to the degree of support required than the degree of exclusion deemed necessary. In this sense multiple axes of identity are possible within community contexts that offer support. At the same time there is recognition that these contexts are not readily available to the intellectually disabled person. There is no evidence of an educational discourse aligned with this perspective.

While I have explored the processes of subjectification in the above discourses, Foucault (1982) reminds us that the process does not only involve being subject *to* but also the subject *of* government. Government is truly effective only to the extent that the individual becomes self-governing. Power is exercised as an action upon an action, a productive power that generates ways in which people conduct themselves. Thus the question that must be asked is not only about external processes (subjectification) but also about the subject's work on him or herself to become a governable subject (subjectivisation) (Hook, 2007). It is at the point of subjectivisation that the current study must come to an end. This is because in Q-study A1 participants were asked to rank statements about people with intellectual disability in general, rather than rank their own views about themselves. While one might make the assumption that they would use their own experience as a starting point, extending this to talking about subjectivisation would be problematic.

Conclusion

In this chapter I have examined the interactions of representational and educational discourses of intellectual disability with respect to their knowledge, power and subjectifying effects. I have argued that the pressure for exclusion in education is exacerbated through disciplinary power that judges relative to the norm, and allocates individuals to their places in the system. The exercise of this power as a force for inclusion through the medico-psychological gaze and the deployment of disability expertise is problematic for this reason. The construction of disability expertise as a scarce, but essential resource, pervades the education system requiring elaborate mechanisms to ensure access in broader settings. This acts as an impediment to inclusive education which then becomes a problem of allocation of resources and shifting expertise from one setting to another (Slee, 2001).

The religious and charity discourse has implications for education both in its form (as a Christian duty) and its content (the construction of the Christian subject). Resistance to the discourses of care and protection is to be found in a human rights discourse. This discourse, it is noted, runs the risk of silencing the marginalised voice of parents as afraid for the safety of their children in poorly resourced and unprepared schools. The tension between autonomy and care is at the root of advocacy practices and interactive and community discourses offer new ways of looking at how this tension can be resolved through consideration of interdependence at personal relations and community levels.

Fundamental to the construction of intellectual disability is the way that impairment is understood. For the most part, it is viewed as a static entity and this inscribes limitations on intellectually disabled subjects. The human rights and interactive discourses begin to erode the static nature of impairment, shifting attention to “becoming” rather than “being”. The intellectually disabled subject in this configuration is not fixed but in process. The nature of this process is obscured by the limited exploration of the subjectivisation of the intellectually disabled person, and possible ways of theorising and researching impairment and subjectivity constitute a concern in the final chapter of this dissertation.

CHAPTER 9: CONCLUSIONS, IMPLICATIONS AND FURTHER DIRECTIONS

My motivation for working in the field of inclusive education theory and practice was at the outset one of an activist. Inclusive education lent a human rights support base to the fight against exclusion of disabled people from schooling and, more broadly, from society. As my engagement in the field continued, I became aware of the extraordinary resistance to inclusive education, the resilience of special education practice and the shifting of special educational strategies into mainstream settings under the guise of inclusion. My initial response was to look to the social model as a paradigm shift that would underpin real educational change (Naicker, 1999). The efforts of activists and parents, I reasoned, should focus on ensuring that a social understanding of disability as distinct from biological impairment enters into educational discourse. I undertook the current study with a view to establishing the extent to which this was happening and how it could be facilitated. My enthusiasm for the social model is evidenced in the high factor loadings my Q-sort had on human rights discourses of *A4.2: Social model/human rights discourse* and *B1: Inclusion as a human right.* However, my engagement with the social model of disability through a post-structuralist lens destabilised my conception of the notion of impairment as unproblematic lack of the body. I was led to question the uncritical adoption of a human rights perspective for intellectual disability and a different journey was started.

In this final chapter, I shall present a review of the main findings of this study. These relate to a) the medico-psychological gaze and disability expertise, b) human rights and c) religious perspectives on disability. On the basis of these findings, I present my central argument for a theory of *(poss)ability,* a neologism that I have found useful in expressing the fluidity and interactional nature of disability emerging from this study. I shall then look critically at the use of Q-methodology in this study, noting especially its application with intellectually disabled people and its use as a discourse analytic tool. Before making my final conclusion, I shall make some suggestions for possible future research directions

The Medico-psychological Gaze and Disability Expertise

In the current study, the overwhelming truth discourse about intellectual disability is that of an individual organic defect, subject to diagnosis by the medico-psychological authority that is responsible for overseeing the application of disability expertise in educational settings. In the best interests of those classified as intellectually disabled, exclusion is rationally and ethically allocated on the basis of differentiating the level of competence or the severity of the disability of the individual.

I have argued that intellectual disability in education falls within the domain of a medico-psychological gaze that employs multiple agents with varying levels of authority in addressing either the organic impairment or the effects of disability. The medical, therapeutic and psychological professions diagnose the inherent lack within the individual (intellectual impairment), relative to the norm of the average intelligence and behaviour that is deemed necessary for participation in regular classrooms. This class of professionals pronounces on the limit of possibility through techniques of assessment, diagnosis and prognosis.

The diagnosis of intellectual impairment mobilises the need for disability expertise, which, as has been noted in chapter 8, is a scarce resource requiring delivery mechanisms and special placement. Disability expertise defines members of a category of troubling (and often troublesome) individuals who mark the limit of success that ordinary teaching can be expected to achieve. Beyond this point lies organic impairment, the endpoint that frustrated Itard’s attempts to teach Victor, the Wild Boy of Aveyron. The impairment, outside of normal diversity and within the domain of the abnormal, can be addressed through the application of professional knowledge applied in the spirit of the caring, compassion and religious values. The professional becomes the guide for the disabled person in an exercise of Christian pastoral power that is authorised by reference to medico-psychological authority.

Understandings of Human Rights

In this study there have been three types of claims to human rights for intellectually disabled people. The first one is a right to full participation and autonomy as evidenced in social model discourses of *A4.2: Social model/human rights discourse* and *B1: Inclusion as a human right*. Secondly, there is a right to appropriate education in *B2: Special needs require special provision*, *B4: Excellent special education as a right* and *B5: Effective education must be tailored to the child's needs*. Thirdly, *B6: Special education keeps children safe* demands the right to protection from harm. The first claim to rights is squarely situated within a disability rights movement understanding of the social model of disability and has been discussed at some length in chapter 2. However, this understanding of rights has been enhanced in this study with the visibility of second and third claims to services (appropriate education) and protection from abuse, respectively.

Young and Quibell (2000) distinguish between positive rights and negative rights. Positive rights refer to the special treatment required to gain equality and specify what should be given in fairness to create equality. In this case claims are made to special educational provision. Negative rights refer to an equality of treatment and specify what cannot be done to a person. In terms of the current study this would be the basis of claims to protection from abuse. Young and Quibell (2000) note that both forms of claims have been unsuccessful in making significant gains for intellectually disabled people. They suggest that part of the reason for this is that negative rights on their own cannot offer protection *before* the abusive act, only redress afterwards. Ultimately they argue that the notion of rights is based on an atomistic individuality that uses rights as a form of protection against each other. As noted in chapter 8, the intellectually disabled person is viewed as irrational and is disadvantaged since "rights cannot be used to empower people whose very participation in a legal framework renders them powerless" (p. 753). They require others to stand up on their behalf and this undermines the project of human rights at the outset, as one of individual autonomy.

What then do we make of rights for intellectually disabled people, particularly with regard to education? Young and Quibell (2000) advocate for a process of understanding each other through listening to the stories of “becoming” of intellectually disabled people. The project is to build relations rather than rights, common interests rather than competing ones, and understanding rather than Otherness (understood in this context as the exclusion of a subordinate group as distinct from one’s own group and thereby defining what one is not). This is not to say that we can afford to abandon the project of human rights for intellectually disabled people but that we need to be critical in the application. Firstly, we need to acknowledge that the universal subject of human rights marginalises the intellectually disabled subject as irrational and incompetent. Secondly, we need to be very aware of who is speaking on behalf of intellectually disabled people and be critical of the notion of “their best interests”. Thirdly, it is important to acknowledge that unless rights are accompanied by an understanding of those to whom these rights belong they are unlikely to be helpful (Young & Quibell, 2000).

The rights of intellectually disabled people should be framed within an ethics of care as argued for by feminist disability scholars, discussed in chapter 8. This ethic is founded on an acknowledgement of interdependent relationships, as opposed to the rigid distinction between carer and dependent. For example, in the accounts of disability as a blessing (*A2.6: A blessing and a gift from God.),* adopted by some parents, the contribution of the intellectually disabled person is readily acknowledged by parents as a spiritual gift. This erodes the notion of the giver and the recipient and acknowledges that interdependence is constructed in many ways, not all of which have to do with competence and the rational self.

The strong appeal to the negative right of protection from abuse that is evident in this study in discourses of care and protection limits the agency and autonomy of intellectually disabled people. This strategy, for which McConkey and Smyth (2003) use the term “danger-avoidance” (p. 27), fixes competence at a certain level in the interests of safety. The vulnerable person is protected and removed from or not exposed to those situations where harm could conceivably arise. McConkey and Smyth (2003) note that this restricts the autonomy of the individual. They argue that the development of competence in different contexts, each with their associated risks, be considered as an interaction between the individual, the context, the collaboration with others and the likelihood of harm. In this way competence is viewed as an interactive performance, not merely an inherent property of the individual that calls for protection on the basis of human rights.

At the same time, rights are not sufficient to protect intellectually disabled people from a hostile community. The concept of *ubuntu* can be drawn on as a protective mechanism. In this view, communities are bound to embrace all who belong within them and to accommodate difference through support. This constitutes a search for competent communities that enable their members to contribute and to gain support, rather than focusing on incompetent individuals. Indeed, as Otto (1999) points out, an uncritical adoption of rights discourse can be dangerous.

Religious Perspectives on Disability

In chapter 8, I noted the importance of religion in understanding intellectual disability in the current study. This significance extends to an understanding of intellectual disability in the professional arena and I contend that it is present in the exercise of disability expertise. This expertise is easily aligned with a representation of intellectually disabled people, within a religious frame, as vulnerable due to their organic deficit (requiring care and protection). This is evidenced in *A4.3: Medical model/religious discourse*. A convergence of old (Christian) and new (disciplinary) forms of pastoral power (Foucault, 1979) places the special educator as the leader of the flock, an intermediary of the superior power of the medico-psychological complex, imbued with the moral force of Christian compassion. The implication of such an alliance is that the child's best interests, as formulated by the disability professionals, become intertwined with religious concepts of redemption and sin. Resistance to the dictates of a medical authority become imbued with a moral waywardness. On the other hand, compliance offers the chance of salvation and moral improvement.

Parents draw on religious ethics, as evidenced in the accounts of Q-study A2, both as an explanation of the cause of disability and a means of coping with it. It was noted that this has either positive (a blessing) or negative (a burden) connotations in different accounts. The fact that it is only parents that draw on the notion of a blessing is worth exploring further, noting that the experience of parents is generally conceived of as a negative one (Stainton & Besser, 1998).

The above findings have highlighted the ways in which a notion of impairment as a fixed property of an individual underpins educational practice. I propose, therefore, a more fluid and dynamic understanding of disability, not as inability, but rather as *(poss)ability*. I shall elaborate on this concept below.

A Theory of (Poss)ability

In my examination of discourses of representation and education of intellectually disabled people, in all except one discourse (*A4.1: Interactive discourse*) the fixed and static nature of impairment underpinned practices of exclusion and imposed a limit on the possibilities open to those classified as "having" impairment. On this basis, I concur with Goodley and Roets (2008) that as long as impairment is regarded as static or fixed it is "open for power takeovers and always at risk of co-, or multiple forms of, morbidity. Disabled people can get disciplined, at any point, by expert professionals and their constitutive regimes of ultimate truth and bio-power at play" (p. 245). A view of impairment as static has had dire consequences for educational practice, restricting opportunity and circumscribing a disabled subjectivity that is dependent and vulnerable, and which poses a burden of care on families and communities. Within educational theory, impairment (because of its intractability) has fallen largely outside the scope of socially just pedagogies resulting in ever new forms of division to deal with a fixed class of impaired individuals (Goodley & Roets, 2008). What then are alternative ways of viewing impairment?

In my examination of discourses drawn upon by the intellectually disabled adults in this study, I was struck by the irrelevance of impairment to these accounts. It was a vague concept, often not even labelled and with a shifting distinction between impairment of the mind or the body. Very few (six out of 22 participants) identified themselves as having an intellectual disability despite being ongoing recipients of services directed at intellectually disabled people. What seemed to be more important is what can be done in what contexts, as embodied in the interactive discourse of A4.1. This raises questions as to the static nature of disability and the limitation that organic impairment imposes. Competence arises within interaction and organic impairment is but one part of a complex array of social meanings that are constructed through discursive and social practices. This is not to deny (or to uncritically accept) physical realities of impairment but rather to recognise that impairment is always and already saturated with meaning and constructive social practices. How then can such an understanding be expanded within a critical disability studies framework?

Goodley (2007) finds the work of Deleuze and Guattari useful in rethinking impairment. He argues that their concept of the rhizome, as a non-hierarchical network of be-coming rather than of being, can be applied to the notion of a learner who is not fixed in the certainty of impairment but rather in the process of becoming and changing without an endpoint in sight. The binaries between disability and impairment, between able and disabled, are dissolved in the recognition of multiple possible relations (Goodley & Roets, 2008). In this view impairment is not conceived of as lack but rather as productive, "constraining and enabling possibilities" (p. 246) in an ongoing process of becoming. I would term this a concern with possibility rather than disability and I therefore suggest the neologism (*poss)ability* to describe a fluid conception of impairment and its proposed concomitant educational practices.

Such a theory entails recognising impairment as a dimension of subjectivity, such as gender, race or sexual orientation, that relates specifically to support and care requirements for achieving competence and social participation. Impairment becomes not an imposition of defect from outside but an integral part of identity that assumes positive or negative value with regard to the way in which it is situated within social practice. It can be stigmatised, as it is currently, or it can be part of a positive identity. It can be included in the daily range of social activity as a feature of diversity that calls upon communities to initiate support practices or it can continue to be relegated to the dark corners and exclusion as the Other, where the solid line of impairment is drawn between the normal and the abnormal.

What would a theory of (poss)ability mean for educational practice? It would align with what Kliewer et al.(2006) describe as a moral journey that begins with inclusion into contexts where "valued membership and the presumption of citizenship are to be found" (p. 187). It is the recognition of belonging and social inclusion that renders impairment a dynamic entity in continual interplay with enabling or disabling environments. Within this frame, and drawing on the theoretical framework outlined in this thesis, specific projects can be identified.

Firstly, intellectual disability would become a dimension of diversity to be dealt with in regular teaching practice, rather than one that requires the application of a specific form of disability expertise. The importance of a familiarity with disability is noted as an element of disability expertise and this could be made readily available to regular schools and teachers. Similarly, there is no reason why love, compassion and understanding should not be found in all schools. An ethics of care that recognises multiple ways of contributing to the classroom community and reciprocity of relationships moves away from the construction of the perpetually needy "special needs child" who is a drain on the resources allocated to more able children. It opens up the potential for recognising and encouraging positive contributions to the learning environment that are not confined to a narrow academic competence but also embrace lessons of learning to live together.

Secondly, the educational interaction would be closely aligned with practices of support that construct competence in varying contexts. In this respect, competence is not seen as a property of the individual but a construction of contexts and participants – competence is both contextual and distributed across social actors (Biklen, 2000). Thus the focus shifts from the inherent limitations of the individual to a continuous search for enabling contexts. As Asch (2001) notes:

> Instead of discussing which kinds of people have impairments or disabilities and which people do not, instead of saying that some members of society are disabled and others are not, we should consider which people cannot perform which activities in given environments and question how to modify the environments so that they are not disabling. (p. 5)

This would require an educational practice of seeking contexts for competence in terms of the types and varieties of activities, the supports required and the relationships called upon. Thus it is not individual incompetence that is the focus of teaching, but rather the context and the relationships that facilitate competence.

Thirdly, a theory of (poss)ability has implications for curriculum. The static view of impairment plays itself out in the curriculum with life skills and functional skills taking precedence over literacy. However, Kliewer et al.(2006) argue that the continuing non-recognition of the ability for literacy amongst those classified as intellectually disabled speaks to a political rather than a scientific project. Illiteracy becomes part of the condition of intellectual disability and there is no attempt to overcome disability, since it is seen as "something static, something beheld from afar, not complex, not shifting in meaning" (Biklen cited in Kliewer, et al., 2006, p. 175). They cite numerous instances of individuals who have made a journey from illiterate non-citizenship to literary participation, indicating that (poss)ability exists where previously only (dis/in)ability was seen. Similarly, education for a wide range of community participation does not occur due to the restricted expectations built on a static understanding of impairment. One example from this study is the uneasiness that surrounds sexuality education that would presume a sexually active adulthood for intellectually disabled people. An educational theory of (poss)ability is just that – one of possibility not one of assumptions of limitation based on fixed conceptions of impairment. The accompanying educational practice is to build competence, both in individuals and in their schools and communities that enables individuals to participate as full citizens in society.

Fourthly, the education of (poss)ability poses a challenge to the notion of diversity and human conduct toward others. It does not only impact on those who are labelled as having impairments but expands the notion of diversity for all learners who are then freed to explore their own subjectivity (Erevelles, 2002; Slee, 2006). Gabel (2002) proposes a practice that strives for an open-ended subjectivity in the pedagogic relationship:

> pedagogy must not conceptualize the subject .The subject should not be preformed as belonging to a particular race, or sexuality, or (dis)ability, or class prior to the pedagogical relationship. Rather, the pedagogical subjects (teacher and student) must emerge within inter- actions in the pedagogical community. (p. 181)

It has long been an argument within inclusive education that it is not only those children classed as disabled that will benefit from inclusion, but also the "typically developing" child (see for example The Salamanca Statement, 1994). However, what has not been equally acknowledged is the way in which disciplinary measures ostensibly directed at children with special needs serve to regulate the entire school population. Deviation from the norm, as the basis of mass compulsory education, is subject to the medico-psychological gaze and disability expertise. The educational practice that would contribute to this is a move away from differentiation and exclusion toward the exploration of multiple learning contexts. .

Fifthly, competence can be more readily located in the community than in the individual. Competence is not only located in the individual but also depends on the extent to which the community is competent to deal with diversity in its midst. A theory of (poss)ability poses the question asked by Touraine (cited in (Slee, 2001, p. 386): "Can we live together?" The educational discourse of *B6: Special education keeps children safe* assumes an incompetent community whereas the discourse, *A4.4: Community/religious discourse* envisages a community that can deal with issues of support and inclusivity. The focus shifts to an exploration of whether the community is competent to include all its members and the support the community needs to provide to families and individuals in order to do so. The educational practice that responds to the project of community competence is engagement with the community and with families and parents to facilitate contexts for competence and inclusion. The notion of parents as either overprotective or abusive runs counter to this aim.

Ultimately the conclusion of this dissertation is that static understandings of intellectual disability have been constructed and perpetuated through the medicalisation and disciplining of difference. A project of emancipation needs to challenge this conception and it can be grounded in a practice of education that espouses (poss)ability rather than (in/dis)ability. What research would support this project and what methodologies can be used most effectively? I shall address this by first looking critically at the application of Q-methodology in the current study and then making suggestions as to further lines of exploration.

The Application of Q-methodology

Quibell (2005) notes that studies that utilise discourse analysis in the field of intellectual disability are largely lacking an empirical base and derive in the main from abstract theoretical sources. In her study of discourse she adopts the view that:

> research is needed to empirically identify, evidence and explore the intellectual disability discourses and how they are expressed in daily life. This is particularly important because different discourses create intellectual disability

> in distinctive ways, and with these constructions of personhood come unique possibilities for resistance and struggle. (p. 84)

Thus I sought, and found in Q-method, a methodology that would capture the everyday flux of discourse, derived empirically from participants themselves. As noted in chapter 5, I worked within the discourse analysis (DA) school of Q-methodology. I chose this method on the grounds that it exposed multiple ways of speaking of a complex topic (R. Stainton Rogers & Stainton Rogers, 1990) within a clearly delineated empirical research methodology. My reflections on the methodology that I utilised are highlighted below.

Engagement of Intellectually Disabled People

Researchers into intellectual disability have long made the plea for greater participation of intellectually disabled people in research, as both participants and researchers (Goodley, 2004; Rodgers, 1999; Walmsley, 2004). Significant modifications were made to this application of Q-method in order to accommodate this need and the benefit of so doing is clear. The accounts deployed by this group of participants differed from the dominant individual-social binary and introduced relational understandings of impairment, which were apparent in *A4.1: Interactive discourse*. Elements of resistance were also noted in the objection to low expectations and stereotyping in accounts *A1.5: A person discriminated against* and *A1.6: A stereotyped person*. These accounts became blurred in the second order study and therefore did not come up for detailed analysis. This has implications for future research, which will be discussed below.

My sense on completion is that I pushed the limit as far as it could go with Q-method in its use with intellectually disabled people. The language used and the ranking procedures were simplified to such a degree that further simplification could have undermined the method itself. It became apparent that even with this degree of simplification, the method used excluded intellectually disabled people who might not have had adequate communication skills but who can and should be given the chance to participate in research about their lives. It would be possible to use items other than statements (pictures for example) in order to gain participation of less literate intellectually disabled people. However, such an approach might render their results incomparable with those of others not similarly challenged. This is not a reason not to explore such a possibility but it also opens up for consideration that other methods might be better suited to those with different communication skills.

Factors as Discourses

A comparison between discourses emerging in this study and those noted by Quibell (2005) suggests that the application of Q-method has yielded comparable results with her Foucauldian discourse analysis (see discussion of rights discourse in chapter 8). The fact that Q-methodology yields an enormous number of possible configurations of the factors (Stenner, et al., 2008) lends a substantial power to the method to reveal the unexpected. In this study the strongly religious protective orientation aligned with medical discourse (*A4.3: Medical model/religious discourse*) did not emerge from an abstract review of the literature alone. The notion of the child as a blessing to parents (*A2.6: A blessing and a gift from God*) and the fluid accounts of impairment (*A4.1: Interactive discourse*) also present unacknowledged ways of talking of disability and perhaps indicate subjugated forms of knowledge that could be further explored.

As a researcher, I have found Q-method an invaluable tool for ordering data in such a way that the researcher has to listen to their participants. Factors are not always easy to interpret at first glance and may seem to contradict one another. If one then examines the configuration in depth and relates this to participant comments, a new perspective that was not within the researcher’s previous understanding can emerge. For example in account *A2.1A: A vulnerable person,* the vulnerability and the capability of the intellectually disabled person are highlighted. This was difficult to understand as they seemed in contrast to each other. The review of comments, though, highlighted the mediation role of the family to the community and structured this as the crucial element that protected or exposed the intellectually disabled person to abuse.

I distinguished between accounts in Q-studies A1, A2 and A3 and discourses in Q-study A4 and Q-study B. This was largely in an attempt to enable diverse voices to be heard (in the accounts) but at the same time to reduce the data for discussion and to look for significant commonalities in the discourses. This is a distinction that can be further explored in Q-method and comparisons of the method with other forms of discourse analysis would be a useful methodological exercise. It can be noted that Q-study B combines two groups of participants in one Q-study and identifies discourses rather than accounts. The data from Q-study B could quite easily be analysed as for Q-study A in two steps, that is two Q-studies, one for parents and one for professionals. This could then be compared to the combined study presented in this dissertation.

Additional Issues Relating to the Application of Q-method

I have noted the limitations of the method with respect to intellectually disabled people. These could be overcome to some extent through the development of a Q-set and Q-study specifically addressed to their perceived needs. As regards other participants, I gained a real sense that the perspectives that they drew on were being adequately represented in the factor analysis and resulting discourses. The use of additional information such as comments and responses to overall questions was tricky to incorporate, as a different order of data from the Q-study outputs, but useful in aiding interpretation. Kitzinger (1985) recommended the interviewing of participants in the study as an adjunct to the Q-sorting process. Referring back to participants is also suggested as a means of validation of the authenticity of the factors identified (Curt, 1994).

I believe that the qualitative data from participants and the quantitative data of the Q-study need to be related to each other in principled ways that depend on the researcher’s understanding of discourse. If discourse is understood to be descriptive of a certain point of view, then the connection to participants is very important. Who are they and why do they adopt this view? If, on the other hand, discourse is seen as constructive of subjectivity, then it is the *effects* of discourse rather than the *possessor* of any one discourse that is of interest. In my view Q-method provided an effective tool for empirically identifying available discourses on education of intellectually disabled people in the East London education district of Buffalo City. These are not the property of individuals but rather delineate the conditions of possibility that constrain and construct possible ways of understanding intellectual disability. However, I have noted in this study where certain groups of people, for example parents belonging to the Down Syndrome Association Amathole (DSAA) or black parents, load onto particular factors. Rather than interpreting this as a view that belongs to this particular group, I would see these discourses/accounts as deployed in particular constraining and enabling micro- and macro-level contexts. Thus a parent support group environment such as DSAA might enable an inclusive type discourse as opposed to a context of a special school that makes professionalised discourses possible.

Future Directions

The research carried out in this dissertation has raised questions about the concept of intellectual impairment that can be pursued in further research. These areas are a) resistance, b) subjectivisation and c) educational policy and practice.

Resistance

The truth that special education poses, imbued with a normalising intent, is that the intellectually disabled person is not only fundamentally and irrevocably different from others, but also that this is a negatively valued difference that places conditions on the subjectivity that intellectually disabled people can adopt. Not for them work, friendships, relationships, marriage and having their own families – they are the sheep of the flock, who, as a long as they remain docile and obedient, will be entitled to care and protection. Resistance to this subject position can be dismissed with reference to organic deficit that causes anti-social behaviour and that justifies the application of restraining and punitive responses (Rapley, 2004; Yates, 2005). In the current study, the moral force of a Christian ethic bolsters this dismissal.

Foucault (1982) argues that it is resistance and the way that it operates that should be examined in order to understand the exercise of power itself. In the current study the form of resistance to a disciplinary power of intellectually disabled subjectivity was presented in terms of a human rights understanding of a social model of disability but intellectually disabled participants did not deploy this discourse. The critical position that I adopt on human rights and the absence of the voice of intellectually disabled people themselves from this discourse, persuades me that there is a need to explore social justice for intellectually disabled people in additional ways.

Gabel and Peters (2004) note that the link that Foucault makes between the individualising and totalising effects of power suggest that resistance at the individual levels has implications for broader social processes. As long as there are unacknowledged sites for the practice of disciplinary power and intellectual impairment is taken for granted as a thing in the world (as is the case within a social model of human rights), then the operation of power remains obscured as a practice of truth. The forms of resistance of intellectually disabled people in this study were evidenced in accounts of discrimination and stereotyping *(A1.5: A person discriminated against, A1.6 A stereotyped person).* These are concerns with the negotiation of competence and the unmasking of power relations, and open up new opportunities for resistance that challenge a restricted subjectivity that constitutes a justification for forms of control. Research that examines the everyday interactions of power and resistance in context where intellectual disability is constructed (see for example, Rapley, 2004 and Yates, 2005) will be useful in this regard.

Subjectivisation

I note with Yates, Dyson and Hiles (2008) that "the ways that people understand and form relationships with themselves and their own conduct" (p. 256) is often neglected in research into intellectual disability. What would such an investigation look like? As I have noted previously subjectification is ineffective if it only operates and is maintained from outside. It is the internal processes of making of oneself a fitting subject, or subjectivisation, that completes the truth of the individual subject (Hook, 2007). The data in this study is tenuous regarding subjectivisation but I would like to draw two points from it. Firstly, intellectually disabled people deploy dominant forms of discourse, except for a human rights discourse. Given that this is a dominant discourse in inclusive education and disability rights arenas, this omission is somewhat surprising and should be further examined. Secondly, the ways in which intellectually disabled people construct themselves as subjects in the educational arena is unexamined in this study (they did not complete Q-study B) and should be further explored. It is only then that the power effects of educational practice can be made visible and therefore challenged.

Any examination of subjectivisation would require flexibility around communication capabilities and styles. Intellectually disabled subjects are often disqualified from speaking because they do not represent a rational autonomy, particularly if they are unable to communicate in immediately recognisable ways (Erevelles, 2005). It is here that the disbelief in the reflexive capacity of intellectually disabled people would have to be suspended to avoid a very easy slippage into constructions of incompetence and biological determinism that cast the intellectually disabled person once again outside the realm and reach of disciplinary power – a mere biological being. Such research would need to explore multiple processes, not all of which would be language based, that inscribe the subjectivity associated with incompetence even in its most inaccessible forms. This would be both a methodological and a conceptual challenge.

Educational Policy and Practice

The adoption of an inclusive education discourse can act as a legitimating device for the unproblematic continuation of special educational practice in new places but under the same supervision and with no threat to the traditional professionals. As Slee (2006) notes: “Inclusive education has permitted all manner of thinking, discourse and activity to pass itself off as inclusive” (p.111). This is evident in the current study in the deployment of disability expertise under the medico-psychological authority. The liberatory intent and the human rights agenda of an inclusive education practice are vulnerable to the constant slippage back to the medico-psychological and disability expertise management of impairment. The concerns of an inclusive education based on this understanding are about technical questions of resources, placement and the distribution of expertise. The narrow view of human rights that it adopts is that of humanitarian aid to a few defective individuals and results in what Slee (2001) terms “reluctant schooling” (p. 381) of those at the margins, rather than inclusive schooling. It is for this reason that the deployment of expertise within inclusive education policy needs to be carefully considered and explored.

Within South African educational policy, it is the solidity of impairment that provides the anchor for disability expertise. Van Rooyen and Le Grange (2003) note that within South African inclusive education policy (as evidenced in Education White Paper 6) “disability itself is not narrated as socially constructed … but [it] is constituted as medical/organic with no reflection on how these medical/organic differences are read” (p. 154). This is consistent with the version of the social model of disability (which is actively espoused within the policy) that was critiqued in chapter 2 and has much in common with the medical model of disability understanding of impairment.

The impairment is conceded to the classification and disciplinary systems that address organic defect. Assessment, diagnosis and intervention procedures are based on a static notion of impairment that requires a form of exclusion at some point and that defines the intellectually disabled subject as one of limited competence and therefore capable only of restricted participation and citizenship. Research in education policy and practice should consider very carefully the impact of classification systems and the deployment of expertise. The development of curricula that enable multiple contexts for the construction of competence can also be explored.

Material Conditions for Intellectually Disabled People and their Families

The discourses of *A4.3: Medical model/religious discourse* and *B6: Special education keeps children safe*, with their emphasis on protection, highlight the difficult material conditions with which intellectually disabled people and their families have to deal. A response to this has been identified as a negative human rights approach (see above), and the limitations of such an approach were noted. Research that describes the extent and nature of poverty and abusive practices should be supplemented by a critical examination of discursive constructions of intellectual disability and the conditions of possibility that form this group as objects of abuse. Obviously all legal and protective measures to prevent and redress abuse must be continued simultaneously. However, for change to occur in communities the need for understanding each other as proposed by Young and Quibell (2000) may be more effective in the long term than an appeal to rights alone.

Conclusions

The starting point of this study was the recognition of the resistance of educational practice to the inclusion of intellectually disabled learners, despite a strong human rights agenda to this end. I adopted a post-structuralist, critical disability studies theoretical perspective and framed my research questions with regard to the operation of power, knowledge and subjectivity in the construction of intellectual disability in educational practice. This entailed a review of representation of intellectual disability and educational practice as constructed within different historical and cultural settings. I chose a methodology suited to revealing a multiplicity of perspectives in Q-methodology of the discourse analysis (DA) school. The resulting accounts and discourses yielded many interesting insights which have been discussed exhaustively in the preceding chapters.

I conclude this thesis with a proposal for a theory of (poss)ability as one that offers potential for change, growth and opportunity as opposed to the static notion of impairment as biological lack of individual bodies that confines and limits by its very definition. My argument is for a change from a discourse of tragedy, limitation and disability to one of hope and (poss)ability. To conclude I quote from my then three-year-old daughter on being told that her baby brother had Down Syndrome, (which was explained to her as meaning that he will have difficulty in learning): “Mommy, I know that he will be slow in learning but will he still be naughty?” The question can be expanded: “Will he play music? Will he fall in love? Will he be a sociable or a reserved person? What work will he like to do? Where will he live? Who might he marry?” And a million other questions that come to mind as we imagine the future, the be-coming and the (poss)abilities of intellectually disabled people.

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APPENDIXES TO THE DISSERTATION

CONSTRUCTING THE INTELLECTUALLY DISABLED PERSON AS A SUBJECT OF EDUCATION: A DISCOURSE ANALYSIS USING Q-METHODOLOGY

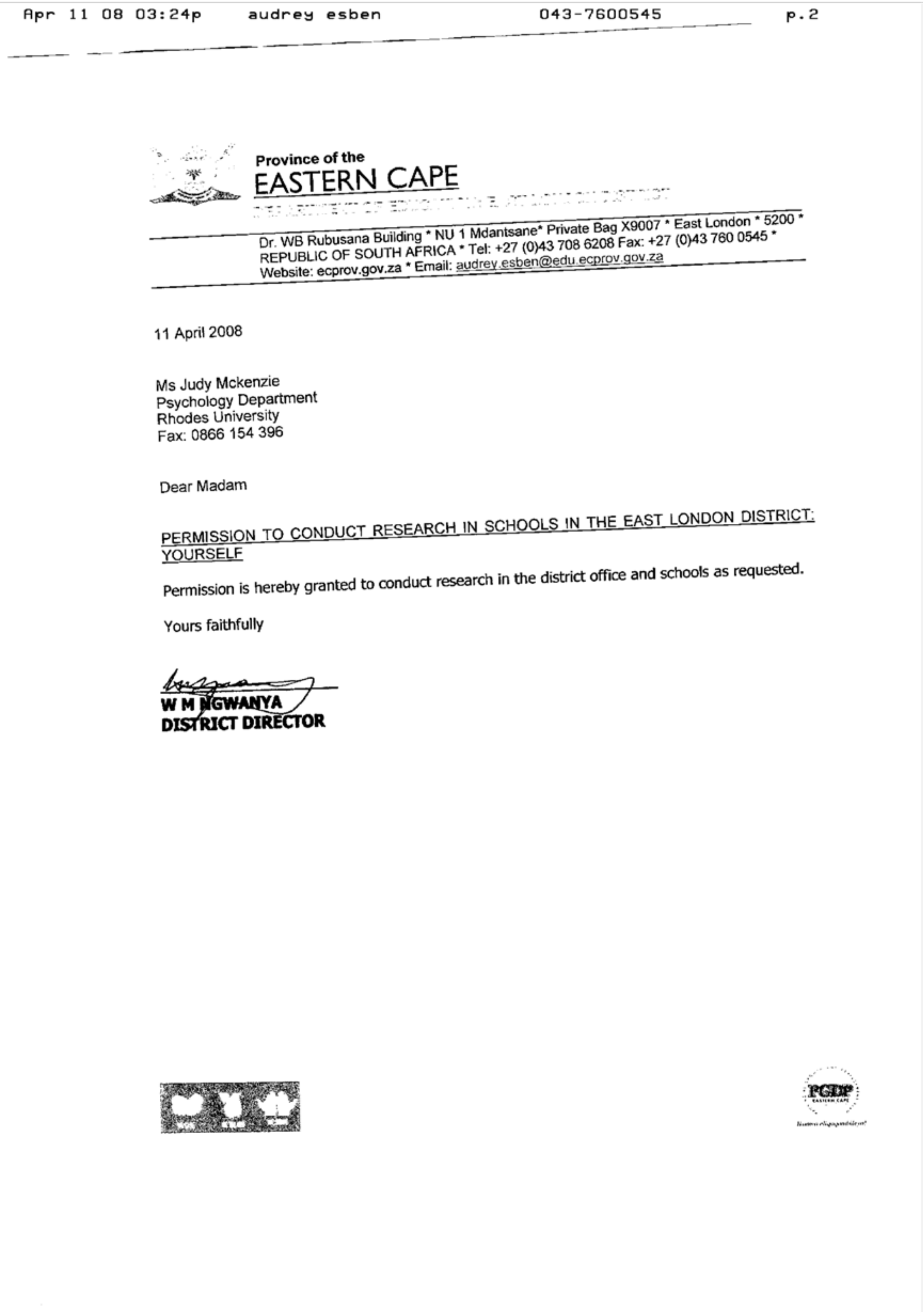
Submitted by

Judith Anne McKenzie
September 2009

List of appendixes

List of tables in the appendixes

Appendix A: Permission from the District Manager: East London Education District



Apr 11 08 03:24p audrey esben 043-7600545 p.2

Province of the
EASTERN CAPE
[illegible]
Dr. WB Rubusana Building * NU 1 Mdantsane* Private Bag X9007 * East London * 5200 *
REPUBLIC OF SOUTH AFRICA * Tel: +27 (0)43 708 6208 Fax: +27 (0)43 760 0545 *
Website: ecprov.gov.za * Email: audrey.esben@edu.ecprov.gov.za

11 April 2008

Ms Judy Mckenzie
Psychology Department
Rhodes University
Fax: 0866 154 396

Dear Madam

PERMISSION TO CONDUCT RESEARCH IN SCHOOLS IN THE EAST LONDON DISTRICT: YOURSELF

Permission is hereby granted to conduct research in the district office and schools as requested.

Yours faithfully

W M NGWANYA
DISTRICT DIRECTOR

PGDP
EASTERN CAPE

Appendix B: Letter to School Principal to Arrange Interviews.

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

The Principal
Parkland Special School
PO Box 15405
Beacon Bay
East London
5205
18 April 2008

Dear Mrs Bartlett,

Background information to request the assistance for interviews of educators at Parkland Special School

My name is Judy Mckenzie and I am undertaking doctoral research at Rhodes University on intellectual disability. This letter serves as background information to a request to interview educators from your school. Permission to conduct educational research in the district has been granted by the District Director, Mr. Ngwanya.

In this study, educators and district officials will be asked to rate their views, from strongly agree to strongly disagree on sets of statements about the education of learners with intellectual disability. This will take approximately 60 - 90 minutes to finish. The form that they complete will have their name and school on it. However, only the researchers will have access to this information. The information will remain confidential, although the participant might be asked to clarify their views to the researcher at a later date. The information will be put together with that of other people and no one individual will be identifiable. The completed forms will be shredded once the study is completed. The name of the district will be given in the study but the names of the schools will be kept confidential, although they might be described in a general way. My request is to interview 5 educators from Parkland

Special School. In addition, I would like to be advised by you as to the best way of recruiting educators and setting up interviews at their and the school's convenience. The forms that the educators from your school complete will look at issues of education of intellectually disabled people. Each participant will sign their own letter of consent once they have read the background information. There are no risks to him/her or the school in participating in this project, nor if the school decides not to participate. The participants from your school will be able to decide not to answer any question or to stop participating at any time, and if so, nothing will happen to him/her. The results of this study do not benefit the school directly, but will contribute to the improvement of the education of intellectually disabled people generally. I would be very happy to give feedback to the school once the project is completed in January 2009. If you have any concerns about the research, you can also contact my supervisor Prof. Macleod, whose details are provided below.

Thank you

Judy Mckenzie   Supervisor: Prof. Catriona
Macleod
Psychology Department   Psychology Department
Rhodes University   Phone: 0466038501
Ph: 043-7265271   e-mail: c.macleod@ru.ac.za
Fax: 0866154396
Cell: 0835000464   e-mail: jocada@computronics.co.za

Appendix C: List of Documents and Interviews Used in the Development of the Q sets

Interviews

1. Inclusion International interviews

- Interview with parents of intellectually disabled children and adults from the Down Syndrome Association Border-Kei (May 2004).
- Interview with intellectually disabled adults from the McClelland work Centre (May 2004).
- Meeting held at the McClelland Work Centre (May 2004).
- Meeting with parents of children with intellectual disability (May 2004).
- Interview with parents of profoundly disabled children at Foden Centre, East London (May 2004).
- Interview with parent committee of a local branch of the Disabled Children's Action Group in Dukathole village, OR Tambo District Eastern Cape (December 2004).
- Interview with children with disabilities in Dukathole village (December 2004).
- Interview with parents of disabled children (Xhosa focus group discussion), (December 2004).
- Interview with manager of Happy Home for disabled children (December 2004).
- Interview with Board member and trustee of Happy Home (December 2004).
- Summary of interview with board members and community members of Happy Home (December 2004).
- Summary of interview with parents of disabled children and community members in Nompumelelo, Lusikisiki. (Xhosa focus group discussion), (December 2004).
- Interview in Thabase Village with disabled children (December 2004).
- Interview with disabled children's home residents (December 2004).
- Field notes Whizz Kids (May 2005).

2. Disabled Children's Action Group Interviews undertaken for an evaluation of the development co-operation between Disabled Children Action Group (South-Africa) and Norsk Forbund for Utviklingshemmede (NFU), conducted by University of Stellenbosch.

- Interview with country manager of NFU (November 2005).
- Interview with community leader, (December 2004).

Project reports

- Field test for the Department of Education conducted by the Sisonke Consortium.
- District Based Support visit No 2 – East London (October 2007).
- District report for on site support visits – Mbizana (October 2007).
- District report for on site support visits - East London (October 2007).
- District report for on site support visits – Lusikisiki (October 2007).
- Meeting with DBST - Lusikisiki (February 2007).
- Report for on site support visit 4 (October 2006).

Media reports from the Daily Dispatch

- *Disbelief, anger as disability grants cancelled* Friday, November 14, 1997.
- *Disability pensioners alerted* By Adrienne Carlisle, Tuesday, December 12, 2000.
- *Project takes education past disabilities* By Justine Gerardy, Friday, May 25, 2001.
- *Special needs schools audit due next month* By Sonja Raasch. Wednesday, June 12, 2002.
- *Outdated attitudes challenged* Friday, October 5, 2001.
- *Intellectually disabled want inclusion* Friday, October 5, 2001.
- *Hysterectomies forced on handicapped women* By Tanya Jonker-Bryce, Thursday, October 4, 2001.
- *Call to remove offensive words* Saturday, October 6, 2001.
- *FAS under spotlight* Saturday, October 6, 2001.
- *EL to host disability conference* By Adrienne Carlisle, Tuesday, September 4, 2001.
- *Down syndrome awareness workshop* By Matthew Ramsden, Wednesday, October 20, 1999 .
- *McClelland to hold open days* By Wendy Sa Joe, Tuesday, March 12, 2002.
- *Inclusive education excluding children with special needs* by Ken Alston, Tuesday, 30 September, 2008.
- *Tumbling into the mainstream* By Toni Muller, Thursday, March 28, 2002.
- *Basic human rights, but only for the able* By Sonia Raasch, Saturday, March 9, 2002.

Journal articles and policy documents

All of the references used in chapters 3 and 4 were drawn on in developing the concourse for the Q-method study. See list of references for the main study.

Appendix D: Completed grid for Factor A1.1

-3	-2	-1	0	1	2	3
2. Their disability is the fault of their mother because of something that she has done wrong	1 They are hidden away from the community.	8. They often find it hard to behave or act in the right way.	37. People should look at the ways in which they are like other people and not look at their difficulties all the time.	36.They are the same as other people in the way they act.	13. They should be taught about friendship, marriage and having children.	32. They treat other people with respect. [
14. They will reach a limit to what they can learn.	40. They cannot manage their own money.	33. They can only work in places where they get support and are kept safe	25. They can do more than many people think they can.	18. When they decide to do something, they take responsibility for their actions.	7. It is very difficult for parents to bring up people like this.	31. They can enjoy art, music and dance.
19. When parents and teachers plan for their future, they do not include the disabled person’s dreams and wishes.	12.They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	9. They can never have their own home.	21. They are always treated well and fairly.	11. They can have a long term relationship or get married.	. 27. They look the same as other people.	28. They are a gift from God
10. They do not know how to stand up for their rights - things that all human beings should be allowed to do or have.	.30. Other people like parents and doctors should not decide what makes their life happy and worthwhile.	5. Brain damage that makes learning difficult stops them from leading a normal life	23. They will always need a lot of help from their family.	24. They bring something into the family because they can get a disability grant.	29. Their parents stop them from doing things because they are worried about what might happen to them.	15. They want to learn how to read and write
[4]	38. It does not matter what you call these people, intellectually disabled or mentally retarded, because the disability is still there.	4. They have not had enough of the right chances to learn.	3. They are more likely to be poor than other people. 6. They must try very hard to be more like other people.	20. They are always made welcome in church and at religious places.	22. They should be brought up within their families no matter what special needs they might have.	
	[5]	16. They are scared of failing in learning.	34. They can be thought of as children in many ways.	39. They can earn money to live on	[5]	

Appendix E: Letter of information for intellectually disabled people

Appendix F: Letter of information to parents and professional participants

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

Study on education of intellectually disabled people in South Africa

Dear participant,
I am undertaking doctoral research at Rhodes University on intellectual disability. I am interested in finding out more about different points of view on the education of intellectually disabled people. The results of this study will be used to get an understanding of the challenges that exist in education for intellectually disabled people. This study does not benefit you directly, but the answers you give together with the answers of all the other people we talk to will be used to find better ways of educating intellectually disabled people.

If you agree to participate, you will be asked to rate your views, from strongly agree to strongly disagree on sets of statements according to the instructions given. This will take approximately 60 - 90 minutes to finish. Only the researchers will have access to the information that links you to your answers. They might come back to you at a later date to ask you to clarify answers in order to get a better understanding of different points of view. The information will be put together with that of other people and no one individual will be identifiable.

The forms that you complete will look at issues related to intellectually disabled people. There are no risks to you in participating in this project, nor if you decide not to participate. You will be able to decide not to answer any question or to stop participating at any time, and if so, nothing will happen to you. If you are uncomfortable about anything arising from the research, you can contact the researcher, Judy Mckenzie or my supervisor Prof. Macleod (see contacts below).

The information gained from the form that you complete will be entered into a computer and analysed with other results. While these results will identify certain details about yourself e.g. age, gender, educational background, your name will not be divulged. The completed forms will be shredded once the study is completed.

Thank you for your time and participation
Signed: ________________________________
Judy Mckenzie
Psychology Department
Rhodes University
Ph/ Fax: 0437265271
Cell: 0835000464 e-mail: jocada@computroniccs.co.za
Signed: _______________________________
Supervisor:
Prof. Catriona Macleod
Psychology Department
Ph/Fax: 0466038501
e-mail: c.macleod@ru.ac.za

Appendix G: Letter of consent for intellectually disabled participants

Do you agree to take part in this project?

Judy Mckenzie is a student at Rhodes University. She is doing a project about teaching and learning for people with intellectual disabilities.

Judy would like to know about what you think about teaching and learning. She would like to know how your disability affects your life. To find out, Judy would like to ask you some questions.

You have been given a letter about the project and what we are asking you to do.

If you are happy to take part in this project, please read and fill in this form.

Your name___________________________________

Do you understand that:

1. Judy is a student at Rhodes University. This project is part of her studies.

2. Judy would like to know what you think about teaching and learning.

3. You will be asked some questions about teaching and learning. It will take about an hour. You can say that you do not want to answer any question.

4. You can talk to Judy if you are worried about taking part. She will look into any issues.

5. You can stop anytime. At the moment you are happy to take part unless anything changes.

6. Your name will not be given in the project report. People will not be able to find out what answers you gave.

By signing this form you are saying that you are happy to take part in this project.

Please sign here:

Judy Mckenzie will sign here:

A witness will sign here:

Before starting:

Judy will ask you these questions to check that you are happy with taking part.

1. What is this project about?
2. Can you stop at anytime if you want to?
3. Who will know what you have said? Will it be Judy or will other people also know?

Appendix H: Letter of consent for parents and professionals

RHODES UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

AGREEMENT

CONSENT TO PARTICIPATE IN THE STUDY
BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

I (participant's name) ____________________________ consent to participation in the research project of ______Judith Anne Mckenzie____________________ on education of intellectually disabled people.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a PhD degree at Rhodes University.

2. The researcher is interested in my views on education of people with intellectual disability.

3. My participation will involve completing a questionnaire which will take about 60 minutes I will be asked to answer questions concerning my views on education but I can choose not to answer any questions if I so wish.

4. I am invited to voice to the researcher any concerns I have about my participation in the study and to have these addressed to my satisfaction.

5. I can withdraw from the study at any time - however I will give my full participation unless some unusual circumstances occur or I have concerns about my participation which I did not originally anticipate.

6. The report on the project will be designed in such a way that I will not be able to be identified by the general reader.

Signed on (Date):

Participant:

Researcher:

Witness:

Appendix I: Tables of results for Q-studies A1, A2, A3 and A4

Table 1: Factor loadings of participants in Q-study A1: Intellectually disabled adults

Note: Calculated at a level of significance of $P<0.01$[1]. Non-significant and confounded Q sorts are shaded. The numbers in each cell indicate the extent to which the individual Q-sort of the participant correlates with the factor denoted in the column heading

Sort	*Participant description and age*	*A1.1*	*A1.2*	*A1.3*	*A1.4*	*A1.5*	*A1.6*	*h^2*[2]
1	White male, 35	25	2	-20	-2	42*	30	38
2	White male, 29	5	4	10	56*	-1	23	38
3	White female, 34	48*	13	8	33	7	13	39
4	White female, 40	16	8	28	51*	33	13	49
5	White female, 54	36	-11	0	29	-1	-8	24
6	White female, 60	55*	-5	-5	-10	11	13	34
7	White male, 24	-2	-23	-2	25	35	61*	63
8	White male, 53	-1	25	23	14	17	-10	18
9	White female, 46	-8	-8	34	20	56*	1	49
10	White male, 36	5	-16	17	10	-20	56*	43
11	White male, 32	13	20	66*	17	28	22	64
12	White female, 30	14	61*	14	22	28	11	56
13	White female, 33	17	16	17	20	25	61*	57

---

[1] This is calculated at a loading of 0.41 or above for this study by PCQ for Windows. Significant loadings are marked with an asterisk.

[2] h^2 indicates the communality of the specific Q sort. It indicates the % of the Q sort that is associated with the other Q sorts in the study (Brown, 1980)

14	White male, 20	56*	-2	28	-10	28	20	52
15	Black male, 21	20	17	23	-17	59*	39	67
16	White male, 19	56*	-4	23	19	14	17	45
17	Black male, 23	27	-1	26	11	54*	20	48
18	White female, 23	20	-5	53*	-2	17	22	40
19	Coloured male, 19	30	5	-8	13	64*	14	55
20	Black female, 20	66*	-11	-11	11	32	5	57
21	White female, 21	41*	19	20	23	52*	-5	58
22	Coloured female, 22	10	[3]-59*	8	10	8	14	41

---

[3] Negative factor loadings that are significant have been made positive through rotation, since this does not affect their loading onto a factor (see Brown, 1980 for discussion). This factor loading is negative since there are two loadings on this factor, but they are in opposition to each other in a bipolar distribution. Hence, this is the only loading that is reflected as a negative number in relation to the other loading onto this factor.

Table 2: Factor array for Q-study A1: Intellectually disabled adults.

Note: The statement is noted in the first column and the response of each factor can be read down the columns numbered 1 to 6. The figures indicate the weighted response for each factor to the statement, rounded off to a whole number of the rating scale.

Statements	*A1.1*	*A1.2*[4]	*A1.3*	*A1.4*	*A1.5*	*A1.6*
1.They are hidden away from the community.	-2	-1	-2	-3	-2	-1
2.Their disability is the fault of their mother because of something she has done wrong.	-3	0	-1	-3	-3	-3
3.They are more likely to be poor than other people.	0	-1	-2	-3	0	-3
4.They have not had enough of the right chances to learn.	-1	1	1	1	0	3
5.Brain damage that makes learning difficult stops them from leading a normal life.	-1	2	1	-1	-1	1
6.They must try very hard to be more like other people.	0	0	-3	0	0	-3
7.It is very difficult for parents to bring up people like this.	2	-1	0	0	-2	-1
8.They often find it hard to behave or act in the right way.	-1	3	0	-1	-1	1
9.They can never have their own home,	-1	0	-2	1	-3	-3
10.They do not know how to stand up for their rights - things that all human beings should be allowed to do or have.	-3	-3	-1	0	-2	0
11.They can have a long-term relationship or get married.	1	0	2	-2	0	-1
12.They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	-2	2	3	0	3	1

---

[4] As noted above, this factor is bipolar. The factor scores presented here indicate the positive pole of the factor , A1.2 that reflects Participant 12 responses. The negative pole, Factor A1.2A is represented by changing the sign of each of these scores.

13.They should be taught about friendship, marriage and having children.	2	0	-1	1	1	0
14.They will reach a limit to what they can learn.	-3	1	-3	-1	-2	0
15.They want to learn how to read and write.	3	1	1	3	3	3
16.They are scared of failing in learning.	-1	-3	0	1	-3	0
17.They are very likely to be abused or treated badly.	-1	0	-1	-2	-1	-2
18.When they decide to do something they take responsibility for their actions.	1	0	-2	-2	1	-1
19.When parents and teachers plan for their future, they do not include the disabled person's dreams and wishes.	-3	-1	-2	-2	-1	2
20.They are always made welcome in church and at religious places.	1	-3	2	2	3	1
21.They are always treated well and fairly.	0	2	-1	-1	2	-2
22.They should be brought up within their families no matter what special needs they might have.	2	3	3	2	1	0
23.They will always need a lot of help from their family.	0	3	2	3	2	1
24.They bring something into the family because they can get a disability grant.	1	3	-1	3	-1	-2
25.They can do more than many people think they can.	0	-2	-1	2	1	2
26.They can give and take love.	1	2	1	0	2	2
27.They look the same as other people.	2	1	-3	-1	0	0
28.They are a gift from God.	3	-2	3	0	2	3
29.Their parents stop them from doing things because they are worried about what might happen to them.	2	-3	0	-1	-1	-1
30.Other people like parents and doctors should not decide what makes their life happy and worthwhile.	-2	-2	-3	-3	0	-1
31.They can enjoy art, music and dance.	3	1	3	1	2	2

32.They treat other people with respect.	3	-1	2	-2	1	1
33.They can only work in places where they get support and are kept safe.	-1	2	2	1	0	-2
34.They can be thought of children in many ways.	0	1	1	0	-1	1
35.They can learn to do most things for themselves with time and patience.	0	-2	0	3	1	3
36.They are the same as other people in the way they act.	1	0	0	2	0	0
37.People should look at the ways in which they are like other people and not look at their difficulties all the time.	0	-2	0	0	-2	2
38.It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	-1	0	-1	1	-2
39.They can earn money to live on.	1	1	1	2	3	0
40.They cannot manage their own money.	-2	-1	1	1	-3	-1

Table 3: Factor loadings of participants in Q-study A2: Parents .

Note: Calculated at a level of significance of P<0.01[5]**.** Significant loadings are marked with an asterisk. Non-significant and confounded Q sorts are shaded. The numbers in each cell indicate the extent to which the individual Q-sort of the participant correlates with the factor denoted in the column heading

Sort	*Participant description and age*	*A2.1*	*A2.2*	*A2.3*	*A2.4*	*A2.5*	*A2.6*	*h²*
1	White male, 52	79*	-14	8	8	8	14	68
2	White female, 49	92*	0	-2	-2	-11	4	86
3	White female, 54	7	8	2	8	-11	67*	48
4	White male, 50	4	-5	14	7	-27	70*	60
5	Black female, 27	-7	58*	10	-7	5	36	50
6	White male, 49	28	5	8	36	38	48*	60
7	White female, 44	27	8	41*	17	14	29	39
8	Black female, 45	17	33	4	2	32	64*	65
9	Black female, 52	25	40	5	23	8	28	36
10	White female, 41	40	-2	38	-4	20	69*	84
11	White female, 40	69*	4	-17	30	11	14	65
12	White female, 53	17	2	42*	5	0	27	29
13	Black female, 41	30	14	39	52*	-4	28	61
14	White female, 31	64*	2	23	13	11	40	65
15	White female, 41	-14	17	8	7	10	67*	52

---

[5] This is calculated at a loading of 0.41 or above for this study by PCQ for Windows. Significant loadings are marked with an asterisk.

16	White male, 30	35	-10	44*	27	2	46*	61
17	Black female, 56	16	10	36	16	52*	11	48
18	Black female, 54	4	2	34	54*	-11	8	43
19	Black female, 51	17	44*	25	-4	-4	38	43
20	Black female, 50	14	28	41*	23	25	38	53
21	Coloured female, 47	14	22	28	-17	14	55*	50
22	Black female, 47	-20	-2	66*	-8	-25	26	61
23	Black female, 44	17	36	53*	-16	-4	8	48
24	Black male, 45	-5	14	11	5	-34	14	17
25	White male, 44	40	-11	7	25	-5	46*	46
26	Black female, 55	-16	42*	25	0	28	28	42
27	Black female, 54	-4	39	8	-8	-27	54*	53
28	Black male, 64	-5	46*	2	28	-5	11	30
29	Black male, 48	-4	7	75*	-4	-5	20	61
30	White female, 49	88*	-2	7	-2	-10	1	79
31	Black female, 44	-8	16	-25	-11	56*	14	44

Table 4: Factor array for Q-study A2: Parents.

Note: The statement is noted in the first column and the response of each factor can be read down the columns numbered 1 to 6. The figures indicate the weighted response for each factor to the statement, rounded off to a whole number of the rating scale.

Statements	*A2.1*	*A2.2*	*A2.3*	*A2.4*	*A2.5*	*A2.6*
1.They are hidden away from the community.	2	-1	-1	0	-1	0
2.Their disability is the fault of their mother because of something she has done wrong.	-3	-2	-3	-3	-1	-3
3.They are more likely to be poor than other people.	0	-3	-1	-3	-3	-2
4.They have not had enough of the right chances to learn.	3	1	1	1	-1	-1
5.Brain damage that makes learning difficult stops them from leading a normal life.	-2	0	2	-3	0	0
6.They must try very hard to be more like other people.	-2	2	-1	-2	0	-1
7.It is very difficult for parents to bring up people like this.	-1	0	3	0	-2	-2
8.They often find it hard to behave or act in the right way.	-1	-2	2	-2	-2	0
9.They can never have their own home.	-2	-2	-2	-1	-2	0
10.They do not know how to stand up for their rights - things that all human beings should be allowed to do or have.	1	2	0	0	-2	1
11.They can have a long-term relationship or get married.	2	-3	-2	0	1	-1
12.They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	-2	1	3	3	1	2
13.They should be taught about friendship, marriage and having children.	2	-1	0	2	0	0
14.They will reach a limit to what they can learn.	-3	-2	-2	-1	1	0
15.They want to learn how to read and write.	1	2	1	2	2	2

16.They are scared of failing in learning.	0	-2	1	-3	1	-1
17.They are very likely to be abused or treated badly.	1	-1	3	1	0	0
18.When they decide to do something they take responsibility for their actions.	0	0	-3	-1	1	-2
19.When parents and teachers plan for their future, they do not include the disabled person's dreams and wishes.	1	-3	-2	2	-3	-1
20.They are always made welcome in church and at religious places.	0	3	0	1	-1	0
21.They are always treated well and fairly.	-3	0	-2	-1	0	-3
22.They should be brought up within their families no matter what special needs they might have.	3	-1	-1	-2	1	1
23.They will always need a lot of help from their family.	-1	3	1	0	0	2
24.They bring something into the family because they can get a disability grant.	-1	-1	-1	1	2	-3
25.They can do more than many people think they can.	2	1	1	2	1	2
26.They can give and take love.	1	1	0	0	0	3
27.They look the same as other people.	0	0	-1	-2	3	-3
28.They are a gift from God.	-1	3	3	2	-1	3
29.Their parents stop them from doing things because they are worried about what might happen to them.	2	1	0	-1	-1	1
30.Other people like parents and doctors should not decide what makes their life happy and worthwhile.	1	-3	-3	1	-3	-1
31.They can enjoy art, music and dance.	1	0	2	1	2	3
32.They treat other people with respect.	0	2	0	1	0	1
33.They can only work in places where they get support and are kept safe.	-1	2	1	3	2	1
34.They can be thought of children in many ways.	-3	-1	0	-1	3	1

35.They can learn to do most things for themselves with time and patience.	3	3	1	-1	3	3
36.They are the same as other people in the way they act.	0	-1	-3	-2	2	-1
37.People should look at the ways in which they are like other people and not look at their difficulties all the time.	3	1	2	3	-1	2
38.It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	0	2	3	-2	-2
39.They can earn money to live on.	0	0	0	0	3	-2
40.They cannot manage their own money.	-1	1	-1	0	-3	1

Table 5: Factor loadings of participants in Q-study A3: Professionals

Note: Calculated at a level of significance of P<0.01[6]**.** Significant loadings are marked with an asterisk. Non-significant and confounded Q sorts are shaded. The numbers in each cell indicate the extent to which the individual Q-sort of the participant correlates with the factor denoted in the column heading

Sort	*Participant description and age*	*A3.1*	*A3.2*	*A3.3*	*A3.4*	*A3.5*	*h²*
1	Coloured, female teacher at Special School (SS), 34	34	28	23	2	59*	60
2	White, female teacher at SS, 51	30	8	32	53*	20	52
3	Coloured, male teacher at SS, 37	56*	-20	7	34	33	59
4	White, female teacher at SS, 46	19	14	-11	40	60*	61
5	White, female, principal , SS, 30	34	17	17	28	56*	57
6	White, female principal, SS, 61	1	-11	27	11	51*	36
7	White, female, health professional, 42	26	-8	73*	28	19	74
8	Black female, community worker, 40	2	36	70*	30	13	75
9	Black female, community worker, 34	29	53*	34	25	17	58
10	Black female, teacher in SS, 45	68*	1	8	0	27	54
11	Black female, teacher in SS, 38	17	23	10	5	61*	48
12	Black female, teacher in SS, 54	13	-2	-7	-14	56*	35

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[6] This is calculated at a loading of 0.41 or above for this study by PCQ for Windows. Significant loadings are marked with an asterisk.

13	Black, female, teacher in SS, 54	39	55*	20	11	26	57
14	Black, male principal, 40	41*	14	5	33	20	34
15	White female health professional, 49	19	-13	60*	39	27	65
16	Black female principal, Full service school (FSS), 49	17	46*	34	-20	20	46
17	Black female teacher in FSS, 38	22	0	44*	8	8	25
18	Black female teacher in FSS, 40	55*	11	20	23	17	43
19	Black female teacher in FSS, 59	14	44*	14	16	-17	29
20	White female district official, 59	32	0	-23	39	67*	76
21	Asian, female district official, 46	19	25	69*	17	8	62
22	Coloured female health professional, 45	35	-14	40	16	56*	64
23	White female teacher in RS, 46	39	16	10	42*	17	40
24	Black female teacher in RS, 44	-2	60*	33	22	5	53
25	Black female teacher in RS, 44	13	35	16	48*	30	50
26	Black female teacher in RS, 37	-1	36	41*	11	35	45
27	Black female teacher in RS, 41	41*	17	11	22	26	33
28	White female health professional, 38	13	0	25	55*	40	54
29	Black male teacher in RS, 37	-30	72*	13	23	28	77
30	Black female teacher in RS, 36	53*	-2	40	-5	50*	69
31	White female teacher in RS, 54	17	28	39	55*	39	72

32	White female health professional, 51	11	-20	35	55*	36	62
33	White male teacher in RS, 46	28	28	42*	23	40	56

Table 6: Factor array for Q-study A3: Professionals

Note: The statement is noted in the first column and the response of each factor can be read down the columns numbered 1 to 6. The figures indicate the weighted response for each factor to the statement, rounded off to a whole number of the rating scale.

Statements	*A3.1*	*A3.2*	*A3.3*	*A3.4*	*A3.5*
1.They are hidden away from the community.	1	-3	0	0	1
2.Their disability is the fault of their mother because of something she has done wrong.	-3	-3	-3	-3	-3
3.They are more likely to be poor than other people.	1	-3	-1	0	-1
4.They have not had enough of the right chances to learn.	3	-1	1	-1	0
5.Brain damage that makes learning difficult stops them from leading a normal life.	0	0	-1	-2	-2
6.They must try very hard to be more like other people.	0	-2	-2	-1	-3
7.It is very difficult for parents/ caregivers to bring up people like this.	-1	1	-1	1	1
8.They often find it hard to behave or act in the right way.	2	-2	-2	-1	0
9.They can never have their own home.	-3	-3	-2	-3	-2
10.They do not know how to stand up for their rights - things that all human beings should be allowed to do or have.	1	-1	-1	1	2
11.They can have a long-term relationship or get married.	-1	1	1	1	0
12.They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	3	3	0	1	1
13.They should be taught about friendship, marriage and having children.	0	0	1	2	0
14.They will reach a limit to what they can learn.	0	-1	-3	1	1
15.They want to learn how to read and write.	-1	1	2	1	0
16.They are scared of failing in learning.	0	-2	0	-1	0

17.They are very likely to be abused or treated badly.	3	1	0	3	3
18.When they decide to do something they take responsibility for their actions.	-2	-1	0	-2	-3
19.When parents/ caregivers and teachers plan for their future, they do not include the disabled person's dreams and wishes.	-2	0	0	0	1
20.They are always made welcome in church and at religious places.	-3	2	-1	-1	0
21.They are always treated well and fairly.	-3	-2	-3	-3	-3
22.They should be brought up within their families no matter what special needs they might have.	0	0	2	0	-1
23.They will always need a lot of help from their family.	0	2	-1	-2	1
24.They bring something into the family because they can get a disability grant.	0	0	0	-1	-2
25.They can do more than many people think they can.	3	2	3	3	2
26.They can give and take love.	1	1	3	2	2
27.They look the same as other people.	-1	3	1	0	-2
28.They are a gift from God.	1	3	1	1	1
29.Their parents/ caregivers stop them from doing things because they are worried about what might happen to them.	1	-1	2	0	3
30.Other people like parents/ caregivers and doctors should not decide what makes their life happy and worthwhile.	-2	1	1	2	-1
31.They can enjoy art, music and dance.	2	3	2	3	2
32.They treat other people with respect.	-1	0	1	-1	-1
33.They can only work in places where they get support and are kept safe.	2	-1	-2	-3	2
34.They can be thought of children in many ways.	-2	1	-1	0	-1
35.They can learn to do most things for themselves with time and patience.	2	2	3	2	3
36.They are the same as other people in the way they act.	-1	2	0	-2	-1

37.People should look at the ways in which they are like other people and not look at their difficulties all the time.	2	0	3	2	3
38.It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	-1	-3	-2	-2
39.They can earn money to live on.	1	0	2	3	-1
40.They cannot manage their own money.	-1	-2	-2	0	0

Table 7: Factor loadings of Q-sorts in Q-study A4: Second order study

Note: Calculated at a level of significance of P<0.01[7]**.** Significant loadings are marked with an asterisk. The numbers in each cell indicate the extent to which the individual Q-sort of the participant correlates with the factor denoted in the column heading

Sort	*Label*	*A4.1*	*A4.2*	*A4.3*	*A4.4*	*h²*
1	A1.1	54*	16	11	39	48
2	A1.3	26	-16	52*	28	44
3	A1.4	51*	-2	36	8	40
4	A1.5	40	-4	22	56*	52
5	A1.6	16	23	56*	40	55
6	A2.1	5	68*	34	0	59
7	A2.2	34	-17	58*	17	53
8	A2.3	-5	-20	70*	20	59
9	A2.4	-19	1	36	41*	34
10	A2.5	58*	4	11	19	39
11	A2.6	7	8	76*	19	62
12	A3.1	-11	32	65*	1	53
13	A3.2	23	16	34	68*	67
14	A3.3	38	78*	34	29	95
15	A3.4	-14	65*	35	29	66

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[7] This is calculated at a loading of 0.41 or above for this study by PCQ for Windows. Significant loadings are marked with an asterisk.

16	A3.5	-25	36	80*	-5	84

Table 8: Factor array for Q-study A4: Second order study

Note: The statement is noted in the first column and the response of each factor can be read down the columns numbered 1 to 6. The figures indicate the weighted response for each factor to the statement, rounded off to a whole number of the rating scale.

Statements	*A4.1*	*A4.2*	*A4.3*	*A4.4*
1.They are hidden away from the community.	-2	1	0	-3
2.Their disability is the fault of their mother because of something she has done wrong.	-3	-3	-3	-3
3.They are more likely to be poor than other people.	-3	0	-2	-2
4.They have not had enough of the right chances to learn.	-1	1	1	-1
5.Brain damage that makes learning difficult stops them from leading a normal life.	-1	-2	0	-1
6.They must try very hard to be more like other people .	0	-2	-2	-2
7.It is very difficult for parents/ caregivers to bring up people like this.	0	0	0	-1
8.They often find it hard to behave or act in the right way.	-2	-2	1	-2
9.They can never have their own home.	-1	-3	-3	-3
10.They do not know how to stand up for their rights - things that all human beings should be allowed to do or have.	-2	0	1	-1
11.They can have a long term relationship or get married.	0	1	-1	1
12.They need speech therapy, physiotherapy and other kinds of help to be able to live a normal life.	0	0	2	3
13.They should be taught about friendship, marriage and having children.	1	2	0	1
14.They will reach a limit to what they can learn.	-1	-2	-1	-2
15.They want to learn how to read and write.	3	1	1	2
16.They are scared of failing in learning.	1	0	-1	-3
17.They are very likely to be abused or treated badly.	-1	1	2	0
18.When they decide to do something they take responsibility for their actions.	0	-1	-3	-1

19.When parents/ caregivers and teachers plan for their future, they do not include the disabled person's dreams and wishes.	-3	0	-1	0
20.They are always made welcome in church and at religious places.	1	-1	0	3
21.They are always treated well and fairly.	-1	-3	-3	-1
22.They should be brought up within their families no matter what special needs they might have.	2	2	0	0
23.They will always need a lot of help from their family.	1	-1	2	2
24.They bring something into the family because they can get a disability grant .	2	-1	-2	0
25.They can do more than many people think they can.	2	3	2	2
26.They can give and take love.	0	3	2	1
27.They look the same as other people .	2	1	-2	2
28.They are a gift from God.	0	0	3	3
29.Their parents/ caregivers stop them from doing things because they are worried about what might happen to them.	0	2	1	-1
30.Other people like parents/ caregivers and doctors should not decide what makes their life happy and worthwhile	-3	1	-2	1
31.They can enjoy art, music and dance.	3	2	3	3
32.They treat other people with respect.	1	0	1	1
33.They can only work in places where they get support and are kept safe.	1	-2	1	0
34.They can be thought of children in many ways.	1	-1	0	0
35.They can learn to do most things for themselves with time and patience.	3	3	3	2
36.They are the same as other people in the way they act.	2	-1	-1	1
37.People should look at the ways in which they are like other people and not look at their difficulties all the time.	-1	3	3	0
38.It does not matter what you call these people, intellectually disabled or mentally retarded because the disability is still there.	-2	-3	-1	0
39.They can earn money to live on.	3	2	-1	1

40.They cannot manage their own money.	-2	-1	0	-2

Appendix J: Tables of results for Q-study B

Table 9: Factor loadings of participants in Q-study B.

Notes: Significant Q-sort loadings are marked with an asterisk.

Insignificant or confounded loadings are shaded.

Factor B3 is bipolar with one negatively loading sort (P26) and four positively loading sorts.

The participant number in brackets indicates the number of the same participant in Q-set A studies.

Participant	*Label*	*1*	*2*	*3*	*4*	*5*	*6*	*h²*
1 (A3: 1)	Coloured, female teacher, SS	57*	19	28	28	8	-17	56
2 (A3: 2)	White, female teacher, SS	10	50*	-11	5	20	17	35
3 (A3: 3)	Coloured, male teacher , SS	44*	33	23	5	17	-22	43
4 (A3: 4)	White, female teacher, SS	-30	61*	13	17	-7	8	54
5 (A3: 5)	White, female, principal, SS	-2	73*	8	1	-19	0	59
6 (A3: 6)	White, female principal, SS	13	7	2	20	34*	-5	18
7 (A3: 7)	White, female, health professional	78*	-5	-5	-20	0	-20	70
8 (A3: 8)	Black female, community worker	65*	-20	-4	-11	23	-20	57
9 (A3: 9)	Black female, community worker	23	8	69*	-30	13	1	66
10 (A3: 10)	Black female, teacher, SS	4	44*	-1	7	11	5	21
11 (A3. 11)	Black female, teacher, SS	-25	53*	17	13	30	8	49
12 (A3: 12)	Black female, teacher, SS	20	25	20	10	-5	47*	38
13 (A3: 13)	Black, female, teacher, SS	5	17	29	27	17	34*	33

14 (A3: 14)	Black, male principal	-2	66*	22	4	-8	-19	53
15 (A3: 15)	White female health prof.	68*	-8	-23	1	20	-29	67
16 (A3: 16)	Black female principal, RS	53*	0	30	-7	19	4	41
17 (A3: 17)	Black female teacher, RS	17	16	13	-8	54*	-1	37
18 (A3: 18)	Black female teacher , RS	58*	2	13	-7	32	25	53
19 (A3: 19)	Black female teacher, RS	17	-2	46*	16	8	-2	28
20 (A3: 20)	White female district official	5	34*	14	54*	8	4	44
21 (A3: 21)	Asian, female district official	73*	-14	-11	-5	20	-22	67
22 (A3: 22)	Coloured female health professional.	46*	-11	2	1	20	-30	37
23 (A3: 23)	White female teacher, RS	-17	46*	1	33	-4	8	35
24 (A3: 24)	Black female teacher, RS	-20	-7	4	35*	-14	2	20
25 (A3: 25)	Black female teacher, RS	-5	5	2	46*	11	20	27
26 (A3: 26)	Black female teacher, RS	-29	5	-47*	-2	-23	-5	38
27 (A3: 28)[8]	White female health professional	45*	20	5	34*	20	-13	41
28 (A3: 29)	Black male teacher, RS	42*	-1	17	28	46*	2	50
29 (A3: 30)	Black female teacher, RS	46*	17	30	8	23	-13	42
30 (A3: 31)	White female teacher, RS	30	54*	-20	16	7	2	45
31 (A3: 32)	White female health prof.	14	65*	-1	-22	23	-2	54
32 (A3: 33)	White male teacher, RS	61*	-14	19	0	16	-10	47
33 (A2: 1)	White male, 52	69*	-11	-26	-11	5	-28	66

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[8] Participant 27 in Q-study A3 did not complete Q-study B.

34 (A2: 2)	White female, 49	72*	-13	-11	-22	-11	-2	62
35 (A2: 3)	White female, 54	-11	32	8	42*	0	32	41
36 (A2: 4)	White male, 50	23	23	-5	46*	-13	23	39
37 (A2: 5)	Black female, 27	23	-10	2	-8	17	39*	25
38 (A2: 6)	White male, 49	27	11	4	0	30	26	25
39 (A2: 7)	White female, 44	81*	-14	8	-2	-5	0	70
40 (A2: 8)	Black female, 45	25	2	-2	19	-5	40*	27
41 (A2: 9)	Black female, 52	28	42*	14	20	-27	28	48
42 (A2: 10)	White female, 41	-26	53*	17	8	-8	23	45
43 (A2: 11)	White female, 40	79*	-11	-17	-5	19	-23	76
44 (A2: 12)	White female, 53	39*	32	32	36*	-14	-27	58
45 (A2: 13)	Black female, 41	55*	22	29	25	-19	30	63
46 (A2: 14)	White female, 31	63*	-5	-7	2	32	-27	58
47 (A2: 15)	White female, 41	-20	53*	23	13	-4	19	42
48 (A2: 16)	White male, 30	23	7	-16	7	34*	-11	22
49 (A2: 17)	Black female, 56	38*	33	7	2	36*	14	41
50 (A2: 18)	Black female, 54	13	20	28	5	-14	5	16
51 (A2: 19)	Black female, 51	23	40*	22	16	-23	25	40
52 (A2: 20)	Black female, 50	-26	20	34*	17	10	32	37
53 (A2: 21)	Coloured female, 47	25	23	14	33	-20	46*	51
54 (A2: 22)	Black female, 47	11	27	-5	44*	8	13	30
55 (A2: 23)	Black female, 44	-28	1	-14	47*	5	16	36

56 (A2: 24)	Black male, 45	11	-10	25	23	-5	2	14
57 (A2: 25)	White male, 44	64*	-17	-23	-19	17	-20	60
58 (A2: 26)	Black female, 55	17	35*	-19	-2	-1	4	20
59 (A2: 27)	Black female, 54	-10	14	23	17	17	35*	27
60 (A2: 28)	Black male, 64	11	40*	-2	5	-19	-1	22
61 (A2: 29)	Black male, 48	-5	11	8	23	11	45*	29
62 (A2: 30)	White female, 49	80*	-8	-7	-4	-7	-4	65
63 (A2: 31)	Black female, 44	28	-20	34*	0	4	14	26

Table 10: Factor array for Q-study B

	F 1	*F 2*	*F 3*	*F 4*	*F 5*	*F 6*
1. Education should empower CYWID to challenge the stigma and discrimination that they often face in the community.	5	1	3	4	-1	2
2. No child should be sent to school away from their family and community because of their disability.	6	-1	-1	2	1	6
3. Parents/caregivers of CYWID often have low expectations of their children	-1	0	1	-2	1	-2
4. Effective education of CYWID is impossible when their families are living in poverty.	-2	-2	-6	-3	-2	-2
5. Parents/caregivers are often unsupportive of the work of the school and educators.	-2	0	1	-2	1	-5
6. Separate community based day care centres run by parents/caregivers are a good option for provision for very severely disabled CYWID.	-2	0	-3	1	-4	-1
7. It is very difficult for parents/caregivers to gain admission for their CYWID into regular schools because these schools see it as a responsibility of special schools.	4	0	0	1	4	3
8. Formal school curricula developed for CYWID are often irrelevant to the context in which these children and youth live and will seek work in.	1	1	-3	-3	-2	-3
9. Social and cultural understandings of disability in families and communities have a big impact on educational provision for CYWID	1	3	-2	2	0	-1
10. There are many useful resources in the community that could support the education CYWID in the local school.	0	-3	0	-4	5	-6
11. The safety of CYWID cannot be guaranteed when they are placed in ordinary schools.	-1	-1	-4	5	-5	5
12. CYWID who are in regular classrooms require the additional support of teacher aides.	0	5	-2	3	0	1
13. The success of education of CYWID depends more on the approach of the particular school and the teachers than on the nature of the disability.	5	1	1	0	0	-2
14. Only children with a mild intellectual disability can be educated in the mainstream classroom.	-4	2	4	-5	3	0
15. It would be harmful if teachers and schools admitted CYWID if they do not have the required specialized skills and knowledge of disability.	-1	5	3	-1	0	0
16. As many as one third of the children in schools in poverty stricken communities can be seen as CYWID,	-1	-1	-5	0	2	-4
17. Regular schools can cope with the education of the majority of CYWID if they focus on a flexible learning programme and a recognition of the learners' strengths	4	-4	0	0	6	2
18. CYWID in regular schools should be promoted with their peer group.	3	-3	-3	-3	-2	-5
19. It is not the responsibility of the schools to organize the specific care and therapy support the child needs.	-3	-6	-3	-3	-3	-5

20. It is impossible to teach CYWID in large classrooms with a linguistically and culturally diverse range of learners.	-3	6	2	-1	-4	1
21. It takes a very special and compassionate person with the right attitude to be an effective teacher of CYWID.	0	5	4	6	6	4
22. It is a very difficult and highly skilled job to teach CYWID.	-5	-2	-1	5	3	3
23. Classmates who are coping well at school can give very effective support to CYWID in the classroom.	4	-1	0	3	1	1
24. Teaching CYWID in the regular classroom places an unfair responsibility on teachers because they have not been trained about disability.	-3	2	0	1	2	0
25. The education of CYWID requires teachers to do much more work such as planning, filling in forms and giving extra time to the learner.	-2	0	0	2	2	2
26. CYWID continue to be better catered for in the white population than in other race groups.	0	2	-4	-1	-3	-4
27. Every CYWID, no matter how severely disabled, can learn and is entitled to an education at the cost of the state	5	2	4	-3	-3	0
28. When CYWID receive an appropriate education, their risk of poverty and exclusion is reduced.	2	0	-2	-1	0	-1
29. It is more expensive to educate CYWID than other children who are not disabled.	-2	-3	-4	3	-1	-4
30. The inclusive education policy is not in the interest of the CYWID but is only intended to save money for the state.	-5	0	-6	0	-6	-4
31. Over time all CYWID will be accommodated in what are currently considered to be ‘ordinary schools’.	1	-5	5	-4	-4	-3
32. Education of CYWID can only take place in the mainstream if there is transformation and change throughout the whole education system.	3	-1	5	1	-1	-6
33. CYWID who are profoundly or multiply disabled need care of nurses and doctors in a safe environment rather than education in school.	-2	2	-5	2	-3	-1
34. IQ score is a very important factor in the decision about whether to place CYWID in special or regular schools.	-6	-5	2	-4	-1	2
35. The aim of education for CYWID is to help them lead productive and useful lives in places for sheltered employment.	-1	-2	3	3	-6	4
36. Teaching methods that focus on rote learning and rigid discipline are a barrier to effective education of CYWID.	1	1	2	-5	2	-3
37. The best way to teach CYWID is through structured programmes with clear goals and positive reinforcement so that they can learn in small steps and experience success.	2	3	0	2	2	4
38. Education of CYWID must develop their ability to take on responsibility.	2	2	5	-4	5	0
39. An important aspect of education for CYWID is to teach the child to communicate with others.	1	4	3	-4	5	5
40. In order to reduce the risk of sexual abuse, CYWID and their parents require education on human development, sexuality and sexual abuse prevention.	2	3	0	-2	3	-1
41. Teaching CYWID to read and write is not a priority as many do not have the intellectual capacity for this.	-3	-4	1	-6	-2	-2
42. Education of CYWID differs according to the medical diagnosis of the child e.g. Down Syndrome, Foetal Alcohol Syndrome	-4	-2	-1	0	0	0
43. Education of CYWID is the same as for all children but requires a lot of time and repetition	0	-4	2	-2	-2	3
44. CYWID need a completely different curriculum to other children.	-5	1	-5	0	1	-2
45. Intelligence tests and IQ scores of CYWID are useful for developing realistic expectations for the child.	-4	-1	6	3	-5	2
46. Education of CYWID is a highly specialized task that is best carried out in small classes where all learners have similar	-6	3	-2	2	-4	-1

problems, separate from the regular classrooms.						
47. Segregated education of CYWID leads to the isolation of children from their peers and society and contributes to the continuing stigma of intellectual disability	4	- 3	2	- 2	3	1
48. CYWID learn more in inclusive education	3	- 6	- 1	- 6	0	0
49. CYWID can do sport and music with the ordinary schools but they need to have their own space for other aspects of the curriculum.	- 3	0	- 3	1	- 3	1
50. Parents of CYWID would choose to send their children to regular schools of they could be certain that they would be safe and have good learning opportunities.	2	- 2	2	- 1	2	1
51. Inclusion of CYWID must proceed gradually so that the infrastructure and teacher training is in place when they are admitted.	0	1	- 1	4	4	0
52. CYWID are treated better and feel more comfortable in special schools and centres amongst people who are like themselves.	- 4	4	1	4	- 1	4
53. Human rights to equality for CYWID can only be achieved through education in inclusive education settings	3	- 5	- 1	- 5	- 2	- 3
54. Education in a mainstream school for CYWID can be a positive experience both for the children involved and for their teachers.	6	- 4	1	0	4	- 2
55. The curriculum for CYWID should focus on the teaching of skills in the area of self-care, domestic skills, use of money, language, and communication.	0	4	- 2	- 1	1	2
56. One of the most important purposes of special schools is to provide help for children to develop their abilities with the support of speech, physio and occupational therapists.	1	4	3	1	- 1	3
57. Currently special schools accommodate many CYWID who require minimal support and should ideally be in mainstream schools.	3	- 2	- 2	0	4	- 3
58. Special schools for CYWID should be strengthened rather than closed down	0	6	6	6	3	6
59. The admission criteria of special schools should not exclude any child on the grounds that they are too severely disabled	2	- 3	4	- 2	- 5	3
60. The staff of special schools have a special love and understanding for CYWID	- 1	3	- 4	5	0	5

Appendix K: Summaries of factors and discourses

Summaries of accounts from Q-studies A1, A2 and A3

A1.1: A competent person.

This account foregrounds the assumption of competence of intellectually disabled people and their desire to learn both academic and social skills. Intellectual disability has a positive connotation in that they are not different from other people in any significant way and have the same aspirations and the potential to achieve these aspirations. The role of the family is important but there is an element of overprotection.

A1.2: A person dependent on their family.

The roots of difference lie in an organic impairment that prevents ‘normal’ engagement with the world. This deficit causes the intellectually disabled to be incompetent in running their own lives and therefore dependent on the family to make decisions for them. Individual autonomy and competence is less valued than the protection of the family.

A1.2A: A vulnerable person.

The effects of an organic impairment make daily life difficult but do not prevent an intellectually disabled person from living a ‘normal’ life. The position of the individual with respect to the family and the community is a more important aspect to consider with respect to normal life. This factor illustrates a struggle with being independent in the absence of family support. There is no protection against abuse and ill-treatment. In the absence of family, the role of religion and the church become central as a site of belonging and support.

A1.3: A person requiring special care and love.

Difference as a feature of intellectual disability and this is not something that needs to be overcome. Rather it is the family and society that must accept and work with difference as part of our common humanity and religious values.

A1.4: An (ir)responsible person.

A distinction is made between more competent and less competent intellectually disabled people. A double perspective of intellectual disability is indicated with a positive image of a keen, motivated learner who takes responsibility for their own learning and an irresponsible person who exhibits anti-social behaviour. Autonomy of the intellectually disabled people is limited because of their own irresponsibility.

A1.5: A person discriminated against.

This account places an emphasis on the equivalence of intellectual disability with other sorts of problems that people might have. As such it is part of the range of human adversity that might affect anyone. It questions why intellectual disability should be singled out for exclusion given that everybody has problems and everybody needs support.

A1.6: A stereotyped person.

Intellectual disability is an organic problem situated in the context of inadequate support and low expectations. The assumption of incompetence by society at large limits the opportunities that they are given. Competence is very important and is something that the individual must strive for but they have the right to appropriate support and education.

A2.1: A citizen with rights.

The level of competence that an intellectually disabled person can reach is often restricted through overprotection and ill treatment. Their degree of social inclusion and autonomy should not be limited by organic impairment since they have the same rights as anyone else to participate fully in the community. While they have a strong place in the family, there is a negative tendency to overprotection that restricts the intellectually disabled person. This is an activist account that mobilises around the unfair discrimination based on perceptions of limitations imposed by organic impairment.

A2.2: An innocent and vulnerable child of God.

Autonomy and independence is extremely limited in this account. An intellectually disabled person is a gift from God, and is special in His eyes. God requires that parents fulfil their duty toward this person by protecting them and preserving their innocence.

A2.3: A difficult challenge to their family.

An intellectually disabled child is vulnerable and incapable of independence. As such they are a challenge to families sent by God. They are very different from others and cannot be expected to take any form of responsibility for themselves.

A2.4: A person with special needs.

An intellectually disabled person has an organic impairment that distinguishes them from other people. They should therefore be taught useful life skills and make a contribution to their family through their life skills and the disability grant.

A2.5: A person to be understood by the community.

The intellectually disabled person is “normal” within the constraints imposed by an organic impairment. A different frame of reference is imposed within the constraint of organic impairment. “Normality” in terms of doing what others in the community do can be achieved with support.

A2.6: A blessing and a gift from God.

This account is similar to Factor A2.2 in that it figures the intellectually disabled person as innocent within a spiritual context. However, the emphasis is more on duty in A2.2 and more on the benefits and joys of an intellectually disabled child in A2.6.

A3.1: A person to be understood and advocated for by professionals.

The distinctive differences of intellectually disabled people expose them to the dangers of an ill-informed and sometimes abusive family and community. Professional knowledge can provide protection against this abuse. The difference that is based in organic impairment can be ameliorated by the development of limited competence through the application of professional skill.

A3.2: A person to be unconditionally accepted by the community.

Intellectually disabled children belong in the community as the difference imposed by their organic impairment is a superficial one. The common humanity of the community is more important than this.

A3.3: A person restricted by a label.

This account approaches claims of intrinsic difference with a high degree of scepticism reflecting a concern with labelling that constructs categories that come to be viewed in a negative light and limit the potential of human beings.

A3.4: A person with an impairment who requires support.

An organic impairment impacts on learning. This difference should not affect the autonomy of the individual but it will affect competence and therefore they should be protected from abuse and provided with appropriate support. .

A3.5: A person with a condition that is an object of expert knowledge.

This account sees intellectual disability as a distinct phenomenon with an organic basis that is amenable to professional intervention. This intervention is based on knowledge about the "truth" of intellectual disability and the appropriate therapeutic actions to be taken. This account as such justifies claims to decide appropriate aspirations for competence and independence, given a relatively hostile and ignorant community and family, through recourse to a superior knowledge of intellectual disability. The "truth" needs to be disseminated amongst the ignorant parents/ caregivers and community.

Discourses of representation of intellectual disability from Q-study A4

A4.1: Interactive discourse.

The intellectually disabled person is in the process of becoming competent through interaction. The judicious provision of support in this process is paramount and supersedes considerations of autonomy and independent decision-making. However, intellectually disabled people must also take responsibility for their own learning. Social inclusion and interaction is crucial to the development of competence.

A4.2: Social model/human rights discourse.

The intellectually disabled person has a right to education in a socially inclusive context regardless of their level of severity or competence. Since autonomy is of the greatest importance, education should be aimed at supporting its development. While the existence of impairment is not in doubt, the impact of this on the development of competence is not apparent in advance. The likelihood of abuse and ill-treatment must be combated through education in human rights for those around the intellectually disabled person.

A4.3: Medical model/religious discourse.

The competence of an intellectually disabled person is limited by organic impairment. They are likely to be abused and ill-treated because of their innocence and incompetence. Education therefore requires the application of specialised techniques to make the most of the impaired intellect and then care and protection must be put in place. It is not likely that they will develop autonomy and therefore skills in this area are not important.

A4.4: Community/religious discourse.

Everyone in the community has some kind of problem and for an intellectually disabled person this problem is limited competence due to intellectual impairment. They still belong within the community and they must learn how to conduct themselves as community members. This requires the acquisition of skills just as much as education of the community to accommodate the difference that intellectual disability makes.

Educational discourses identified in Q-study B

B1: Inclusion as a human right.

Overall this is an account that favours inclusive education as a human rights issue that underpins integration into the community. Inclusion does not only benefit people with disabilities and their families but benefits the community as a whole insofar as it promotes human rights of all citizens. The focus of education should not be on specialised technologies directed at individual deficit within the child but rather on the development of a curriculum that is flexible and supportive. The ‘specialness’ of intellectual disability and its concomitant teaching practices is rejected in favour of an account wherein it is one aspect of diversity within a classroom and it can be dealt with by adapting the school environment. The intellectually disabled child belongs in the regular classroom regardless of their level of competence. The emphasis is not on what they need to be able to do in order to get into the classroom but what support they will need to develop competence. Within this understanding the severity of the disability is immaterial because it does not affect the obligation to provide an inclusive learning environment.

B2: Special needs require special provision.

In this account inclusion is not desirable even if substantial changes were to take place in the education system as a whole. On the contrary, inclusion represents a violation of disabled children’s rights because regular school classrooms are too big, their teachers are not trained and other children will bully them. Special schools are preferable because it is here that you will find teachers who are caring and compassionate and an educational programme that is suited to the needs of CYWID, which are very different to ‘normal’ children. Different educational placements apply to different categories of learners according to severity of disability or competence levels. While the family and community are not perceived as helpful, compassionate teachers can meet their needs.

B3: Inclusive education is a dream of the future.

Inclusive education is desirable but difficult to achieve. This is largely because children who are seen to have very severe disabilities cannot be accommodated in the mainstream. They need specialised skills and technologies that are only available in the special school system.

B4: Excellent special education as a right.

Education for CYWID should focus on the development of marketable skills, rather than life skills that can be taught in the home. This is best done through special schools that are separate but equal to ordinary schools. Extra resources might well be required to ensure that they receive the additional technical skills and equipment that they need to learn on account of their disability. There is little support in the community and it falls to special schools and families to meet the needs of CYWID. There are different levels of competence and some CYWID are too severely disabled to be able to benefit from education.

B5: Effective education must be tailored to the child’s needs.

This account does not treat CYWID as an homogeneous group with identical needs. Diversity within the group is acknowledged and the necessity of tailoring educational provision to specific individual needs is highlighted. The major dimension of diversity within the category is severity of the disability. This requires the provision of a range of placements, from a care environment for the most severely disabled to the mainstream for the more competent. Change needs to occur within regular schools to increase inclusion. Families and communities are not central to this account. Of central importance is the understanding of the unique needs of each individual and meeting these needs through careful consideration and the development of appropriate curricula.

B6: Special education keeps children safe.

This account presents a strong rejection of inclusive education because the classes are too large in regular schools, the teachers are untrained and know little about disability and CYWID will not be safe in these schools. In contrast, special schools provide therapy, expertise and a compassionate understanding of disability. In these schools severity of the disability should not be a consideration and all CYWID should be taught life skills that will prepare them for sheltered employment. The family is central to this account as it is within the family and the special schools that CYWID will find love and support in the face of a hostile community.