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2014-04-02
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AN ANALYSIS OF THE TRAINING OFFERED TO MEDICAL STUDENTS REGARDING THE ASSESSMENT AND TREATMENT OF INDIVIDUALS WITH AN INTELLECTUAL DISABILITY

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Research Report submitted in fulfillment of the requirements for the degree of

Master in Public Health (MPH)

at the

University of the Witwatersrand

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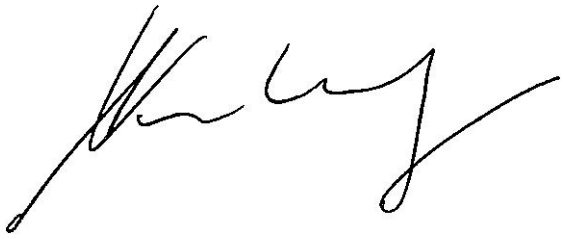
September 2013

DECLARATION

I, the undersigned, hereby declare that the work contained in this research report is my own original work and has not previously in its entirety or in part been submitted at any University for a degree.



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ABSTRACT

Introduction: Individuals with ID have the same or greater health needs than the general population but it is being compromised by diagnostic overshadowing, poor medical management, inappropriate medical technology and insufficient or inappropriate training of health professionals. This study looks specifically at the training which is offered to undergraduate medical students at Wits University in order to prepare them for the appropriate care of individuals with an intellectual disability (ID).

Materials and Methods: The study used a combination of qualitative methodologies. A retrospective record review of all curricular material prescribed and distributed by curriculum implementers to medical students was conducted and analysed. In total, 18 key informants were purposively selected on the basis of being involved in curriculum development and or training of medical students. Three focus group discussions were held with 15 students. Thematic content analysis was used to analyse data.

Results

Teaching Materials and Methods: The teaching materials and methods used to cover the subject of ID were diverse and in many cases not specific to ID. Differences in the quality and nature of training offered on clinical rotations were highlighted and the practical exposure to patients with ID was found to be limited and mostly opportunistic. The latter was both due to a lack of specific focus on the subject and a reported shortage of time to cover all necessary core competencies.

Comparison with the Lennox and Diggens Model with Respect to Teaching in the Areas of ID

Of the five aspects of knowledge, four were found to be thoroughly covered by at least one department and the aspect which was the least well represented was that of 'principles and philosophies of health care for persons with ID.' All four skills aspects were found to be thoroughly covered by at least one

department although two areas, ‘communication with people with ID and their families’ and ‘resourcing information from carers and other sources’ were found to be the most lacking.
The attitudes section fared the most poorly of the three areas with 4 of the 6 aspects being thoroughly taught by one department only.

Appropriateness of the Teaching Materials and Methods: In general, the current training was considered to be inadequate and/or inappropriate. This was mainly attributed to a severe lack of contact time in which to teach the students the subject matter and this was further complicated by the subject of ID not being considered as a priority when competing against epidemic diseases such as HIV and emergency medicine.

Discussion, Conclusions and Recommendations: The study found that Wits medical students are taught about the subject of ID to varying degrees across the Departments of Human Genetics, Paediatrics, Neurosciences and Family Medicine. Although 12 of the 15 aspects of the Lennox and Diggens model have been thoroughly covered by at least one of the aforementioned departments, much of the teaching is generic in nature and not necessarily specific to ID only. Lecturers and students alike felt that the students will complete their studies with a very basic knowledge of the subject of ID, but the students expressed that they are apprehensive about treating patients with ID unsupervised and about their ability to manage complicated cases. The most significant shortcoming of the training was found to be the lack of planned clinical exposure of students to children, and especially adults with ID and this was attributed both to insufficient time within the syllabus and an unfocused approach to the subject itself.

As a result, the recommendations are that a specific module on intellectual disability be included within the Wits syllabus to allow at least one department to dedicate sufficient time and attention to the subject, and that planned practical clinical exposure to patients with ID be included in the syllabus.

ACKNOWLEDGEMENTS

My sincere gratitude is expressed to all of the key informants and undergraduate medical students who sacrificed their time to participate in this research and share their insight. In addition I would like to thank the Dean for granting me access to conduct the research and approach the students for their opinions within focus group discussions.

In particular, I would like to single out and thank my supervisor, Ms. Prudence Ditlopo, for her unwavering support and guidance throughout the conducting and drafting of the research and for her invaluable input throughout the process.

I would also like to acknowledge my mentors and colleagues at Special Olympics, particularly Dr John Dow who not only piqued my interest in this most deserving segment of our population, but also gave me the liberty to pursue my research alongside my work. I hope that in some small way this research will help to further the progress of this important movement and create the levels of equity that we aspire to.

GLOSSARY

CHSE	Centre for Health Science Education
FGD	Focus Group Discussion
GEMP	Graduate Entry Medical Program
ID	Intellectual Disability
IQ	Intelligence Quotient
OSCE	Objective Structure Clinical Exam
SAIDA	South African Inherited Disorders Association
WHO	World Health Organization
WITS	University of the Witwatersrand

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction

Prevalence studies of intellectual disability (ID) globally have produced varying results ranging from 0,33% (Beange & Taplin, 1996) to the much higher rate of 1-2,5% recorded by Gillberg & Soderstroom in 2003 and even rates of 2-3% as referenced in the American Psychiatric Association's Diagnostic and Statistical Manual in 1994. The fluctuation in rates can be attributed to the lack of a clear definition of ID, assessment method and the associated lack of a description of the methods used to select participants (Richardson, 1989). These figures including variations are mirrored in South Africa where individuals with ID make up between 0,27% (Statistics South Africa, 2007) to 3.6% of the population (Christianson, 2002) depending on methodologies used.

ID is defined by The American Association of Intellectual and Developmental Disabilities as *'a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills and originates before the age of 18'* (AAIDD, 2010). Intellectual limitations refers to an Intelligence Quotient (IQ) which falls two standard deviations below the population mean of 100 (<70), and *'adaptive behaviour is the collection of conceptional, social, and practical skills that are learned and performed by people in their everyday lives'* (AAIDD, 2010). This definition has recently been revised by the WHO's International Classification on Diseases (ICD) Working Group to include ID within 'Intellectual Developmental Disorders' which are defined as *'a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior and skills'* (Salvador-Carulla et al, 2011). The Weschler Adult Intelligent Scale further defines the levels of ID according to an individual's IQ and this definition is being updated by the ICD to include clinical characteristics. Currently the subcategories are separated as follows: profound ID being an IQ of lower than 20, severe ID between 20-34, moderate ID between 35-49, mild ID between

50- 69 and, finally, borderline ID between 70-79. In this study only the first, second, third and fourth IQ groups of the Weschler Adult Intelligent Scale will be referenced when referring to individuals with ID, excluding those individuals considered to be borderline. The reason for this selection is that individuals with profound, severe and moderate ID have a higher morbidity and lower life expectancy than the general population including those with borderline ID (Krahn, 2006).

Aside from the obvious syndromic nature of some causes of ID that affect the rates of disease progression, many factors have been identified as contributing to this increased morbidity and mortality of individuals with ID. These include access barriers to health care, an inadequate standard of health care available and, relevant to this study, the nature and quality of training offered to health care professionals (Illet, 2005; Beangue, 1995). Research in Canada, Australia and the UK indicates that the majority of senior residents and general practitioners interviewed felt that the training offered to medical students regarding intellectual disabilities, both at undergraduate level and post graduate level (psychiatry residency), was inadequate in terms of the quantity, content and method of instruction (Burge 2002; Lennox, Diggens & Ugoni 1997; Bradley 1988). This contributed to a poorer level of care and delayed differential diagnoses. To illustrate further the implications of inadequate training being given to health care professionals, in a study in Northern Sydney, Australia, 42% of medical conditions went undiagnosed in people with ID and half of the diagnosed conditions were inadequately managed (Beange et al 1995).

At most universities studied in the literature, ID is included in the curriculum. However, the content, quality, nature and degree of instruction continue to leave medical students with inadequate skills, knowledge and the appropriate attitude with which to manage patients with ID effectively (Lennox & Diggens, 1999). Studies at the University of Cape Town in South Africa, and New South Wales in Australia found that interventions such as the inclusion of practical rotations with home visits and a placement at a special needs school during paediatric rotations resulted in students having a better

understanding of children with special needs (Henley, 1999; Jones, 2007). Similarly, students who were exposed to experiential learning involving adult patients with ID experienced a greater comfort level in assessing and treating individuals with ID (DeLucia, 2009). The importance of this practical exposure is further emphasized by a study in which Shah describes that medical students were found to gain a thorough theoretical knowledge of the diagnostic criteria and core symptoms of Autism, but little knowledge of the aetiology, prognosis and clinical treatment of these patients (Shah, 2001). Should this be the case for other forms of ID, one can extrapolate the direct correlation between a medical student's training and their ability to manage patients with ID.

Given the above information, this study aims to analyze the training offered to undergraduate medical students at Wits to determine the extent to which these students are exposed to the subject of ID during their undergraduate years, as a means of preparing them to care for patients with ID. It is probable that their training may have ramifications for the quality of care that these students might provide to such patients post-qualification.

1.2 Literature Review

The health status of individuals with ID in South Africa suggests that this vulnerable population group have unmet health needs and the literature above suggests that medical schools may be contributing to the extent and quality of care offered, by providing inadequate and/or inappropriate training to medical students (Illet, 2005 ; Beangue 1995). In this section, international and local literature on disease burden, health care utilization, training of health professionals and the Lennox and Diggens model will be reviewed. The section will end with a detailed description of the conceptual framework.

1.2.1 Increased Disease Burden amongst Individuals with ID

Several scholars have documented the prevalence of certain health conditions amongst individuals with ID. For instance, individuals with Down Syndrome are reported to be three to four times more likely to have cardiac conditions than those without Down Syndrome (Horwitz, 2000). Higher incidences of cerebrovascular disease and increased risk of death due to chronic obstructive pulmonary disease, especially amongst institutionalized individuals, are also mentioned as prevalent (Horwitz, 2000). Individuals with ID also have increased prevalence of ocular abnormalities (Evenhuis, 1995) and up to 7 times more frequent cases of dental decay than those without ID (Horwitz, 2000).

Despite the occurrence of significant variations due to the severity of the ID and the diagnostic measures applied, individuals with ID have been reported to have a 3-6 times greater prevalence of mental health disorders than the general population (Horwitz, 2000). Based on clinical diagnosis alone, point prevalence of mental ill-health was found to be 40,9% in a UK based study and the most common disorder related to behavioural abnormalities (Cooper et al, 2007).

Reduced life expectancy is also reported amongst this group, with a life expectancy that is 20 years lower amongst individuals with severe ID than those without ID (Janicki et al., 1999). Individuals with ID are also reported to be unable to manage their weight, which results in up to 42% being underweight while obesity was almost 3 times higher amongst this group than that of the general population (Rubin et al, 1998).

In addition to the above, studies in South Africa attribute conditions such as nutritional deficiencies and growth stunting, Neuro-AIDS and Tuberculous meningitis not only as causative, but often as co-morbid conditions to ID too (Adnams, 2010). The most significant of which is the prevalence of HIV/ AIDS amongst the disabled population which is estimated to be 14% (UNGASS Report 2010).

1.2.2 Utilization of Health Care Services by Individuals with Intellectual Disability

The apparent raised disease burden in the ID population described above has an impact on the health care needs of this population. This is reflected in a study in which children with ID recorded 1.5 times more doctor visits and 3.5 times more hospital stays than their more able compatriots (Boyle, Decoufle & Yeargin-Allsopp, 1994). These figures were mirrored in a study in the Western Cape, South Africa which found the average number of public health care facility visits by children under 12 years with Foetal Alcohol Syndrome over 12 months to be 8 visits – far higher than the mean for all children which was 2,57 visits per annum (Credé, 2011). These utilization rates are not limited to the period in which the patient with ID is a child as significant improvements in life expectancy have been recorded since the 1990's and this has resulted in an increased incidence of chronic and age related diseases which require additional health care visits (Janicki et al, 1999).

Utilization rates are skewed in South Africa as a result of the location of the services and the indirect costs associated with their access. Specialized health services including those for individuals with ID are few and largely focused in urban centres in South Africa (Adnams, 2010). This results in increased indirect costs for those located in rural areas to access specialized services and in turn impacts on their utilization rates.

The increased disease burden in the ID population and the high healthcare utilization rates over their extended lives, particularly in urban areas, increases the likelihood of individuals with ID accessing public health services and therefore increases the likelihood of them interfacing with inadequately-trained health care professionals (Lennox & Diggens 1999).

1.2.3 Training of Health Professionals

The need to train health professionals adequately on the subject of ID has not only been identified by academics such as those referenced in this report, but by students themselves too. The literature

suggests that medical students often feel that the subject of ID has not been adequately covered during their training and they thus feel unprepared to manage individuals with ID (Piachaud, 2002; Messent, 2002). A study in the UK found that 25% of the medical schools surveyed did not include ID in the curriculum at all, whilst others included it to some degree in related subjects such as rheumatology, general practice and geriatrics (Marshall, 1990). Curriculum developers and implementers in some cases acknowledge that the subject is not adequately covered and cite a competitive and limiting schedule of subjects to be covered as justification for this (Lennox & Diggens, 1999). Despite this, universities that do include ID often cover it appropriately across a wide range of departments, including psychiatry, paediatrics and community medicine, thereby increasing the likelihood of the subject being adequately covered (Lennox & Diggens, 1999).

Amongst universities and faculties implementing curricula involving ID, various teaching methods have been applied with varying success, but most notable is that it is not only the content that is relevant, but the manner in which it is covered which determines its efficacy (Jones, 2007). Two studies in South Africa and Australia documented the practical application of managing children with ID in their homes or at a special school to be an effective means of equipping students with the appropriate skills whilst also changing their perception towards ID (Henley, 1999; Jones, 2007). Additionally, examples of practical teaching methods involving theatre and actors who have ID (Hall & Hollins, 1996), un-facilitated interactive sessions between individuals with ID and medical students (May, 1994) and engaging sessions between students and families of individuals with ID (Andrew, 1998) all proved effective in changing attitudes and transferring knowledge and skills to the students.

It is interesting to note that many of the above interventions are aimed more at teaching skills and changing attitudes than transferring theoretical knowledge. This is apt since the two health professional training areas identified by Tuffrey-Wijne as underserved are communication difficulties by the patient or carer/ comprehension by the medical professional and “negative attitudes of health

care professionals possibly caused by lack of confidence, lack of experience and assumptions" (Tuffrey-Wijne, 2003). These aspects are also included with the Lennox and Diggens curriculum which highlights Knowledge, Skills and Attitudes as the three focus areas.

1.2.4 Lennox and Diggens Model

In order to conduct a comparison between the teaching of ID at various Australian Universities, a framework was developed and described by Lennox and Diggens (1999) and has been selected as the comparative reference point in this study. The framework was developed by obtaining opinions from three Psychiatrists, three Paediatricians, one General Practitioner and one psychologist who were all considered experts in the field of ID and had considerable clinical and teaching experience (Lennox and Diggens, 1999). Independently, these experts were asked to list, under the headings of Knowledge, Skills and Attitudes, which aspects of health care for individuals with ID should be taught to undergraduate medical students. Their responses were collated to form 15 essential and priority-ranked points to be included in a curriculum, as depicted below:

Table 1: Conceptual Framework

Lennox and Diggens Model	
Knowledge	
1.1	Knowledge about the nature, frequency and causes of ID.
1.2	Common health and behavioural problems in people with ID.
1.3	The impact of ID on the individual and his/her family
1.4	Community resources, services and useful medical and non-medical referrals
1.5	Principles and philosophies of health care for people with ID
Skills	
2.1	Skills relating to communication with people who are intellectually disabled and their families
2.2	Examination, assessment and diagnosis of people who have ID
2.3	Appropriate referral to and ability to access and liaise with community organisations and

	specialists
2.4	Resourcing information from carers and other sources.
2.5	Skills relating to communication with people who are intellectually disabled and their families
Attitudes	
3.1	To treat people with ID as an equal
3.2	To look beyond the disability and see the person first
3.3	To have respect and appreciation of the rights of people with ID
3.4	To be open to examining one's own attitudes
3.5	Respect for carers information and opinions
3.6	Respect for the wishes and beliefs of people with ID and their families.

While this may not represent the only framework available, it has been selected as the framework for this study as it has been used in previous studies, including as the frame of reference used by Lennox and Diggens (1999) in their review of Australian medical schools and referenced by Piachaud (2002) in his study of a curriculum to be offered in UK Medical schools. It also presents a more comprehensive curriculum to that described by Burge (2008) in his assessment of teaching offered to medical students in selected Canadian universities and that described by Kahtan (1994) on teaching disability and rehabilitation. The model is also considered favourable as it covers three broad areas relating to teaching ID, namely knowledge, skills and attitudes, rather than the narrow view of knowledge only as often reflected in examination methodology.

The Lennox and Diggens model has only been used in developed countries, specifically Australia and countries within the United Kingdom and its applicability to developing countries remains unverified since no literature could be found on its application in low or middle income countries. For this reason too, the Lennox and Diggens model was selected for this study as a means of determining its applicability to a low-middle income country such as South Africa.

The Lennox and Diggens model is of particular relevance in this study due to the nature of the intellectually disabled categories selected (mild, moderate, profound and severe). Individuals with more severe ID have greater limitations with respect to communication and comprehension than their borderline disability counterparts (Beange, 1995), emphasizing the importance of the communication skills necessary to treat these ID patients. Additionally, the syndromic nature of the intellectual disabilities associated with IQs below 69 suggest that thorough knowledge of the aetiology and underlying pathology of a patient with ID are critical components in the success of their case-management (Horwitz, 2000). Finally, although attitudes tend to prevail against all individuals with ID, it does appear that individuals that are more severely affected or have physical signs are prone to more discrimination (Tuffrey-Wijne, 2003), hence it was important to select a model that reflected the degree to which attitudes are addressed in the curriculum.

1.3 Study Objectives

1. To examine the material and methods used to teach medical students in the assessment and treatment of individuals with ID at the University of the Witwatersrand (Wits).
2. To assess the extent to which training offered at Wits fulfils the criteria of an 'ideal curriculum', as described by Lennox and Diggens (1999).
3. To explore the perceptions of the medical students, medical teaching staff and stakeholders of Wits on the appropriateness of training being offered to medical students in the assessment and treatment of individuals with ID.

CHAPTER 2: MATERIALS AND METHODS

2.1 Introduction

In this chapter, the methodology that was used to conduct the study is discussed. The chapter will start by describing the study design, site and the participants to the study. Thereafter the various aspects of the data will be described including the collection method, analysis plan and the manner in which the data was managed and quality assured. Finally this section gives an overview of the ethical considerations relevant to the study.

2.2 Study Design

The study used multiple complementary qualitative methodologies to describe the extent and perceived appropriateness of the curriculum at Wits in preparing medical students to manage patients with ID. The methodologies that were used involved:

- Curriculum review and analysis
- Key informant interviews with Curriculum Implementers
- In-depth interviews with key external stakeholders
- Focus group discussions with medical students

These various methodologies were used in order to create a holistic picture of the teaching by analyzing all angles of the curriculum from the various perspectives involved. This also allowed the findings to be corroborated from various sources and allowed strong themes to emerge across the different methodologies. The Lennox and Diggens curricular framework provided a useful structure as it was applicable across all of the methodologies and allowed for a consistent approach to analysing the subject.

A few teaching frameworks such as that posed by Khatan et al (1994) exist, however the focus of the framework was on teaching about disability in general, rather than ID specifically. Piachaud on the other hand made recommendations on teaching learning disability to medical students and cited the Lennox and Diggens model, but failed to propose a curricular framework from which to develop and test a teaching module (Piachaud, 2002).

The Lennox and Diggens framework had been applied in analysing teaching of ID across Australian universities, however it was limited to a quantitative study with a narrow scale that drew on perspectives of curriculum implementers only. Qualitative studies, including one in SA were found to analyse particular ID teaching interventions only, rather than the curriculum at large and in most cases they drew on the perspectives of students only to determine their results (Henley, 1999). As a result, the application of the Lennox and Diggens framework across multiple methodologies in a qualitative study and in South Africa was both unique and allowed a comprehensive picture to be drawn of the current teaching of ID at Wits University.

2.3 Study Site

The University of the Witwatersrand (Wits) Medical School was selected as the study site due to its convenient location and association with the School of Public Health. Wits is one of the oldest and biggest medical schools within South Africa, thus providing an experienced academic staff from which to draw appropriate interviews. Wits is also compliant with the Health Professionals Council of South Africa's Curricular Standards and has recently restructured some of its courses to meet international standards, which is particularly relevant for this study as it provides a comparison with an international curriculum for the teaching of the subject of ID. The research was conducted within four departments at Wits' Medical School, namely Human Genetics, Neurosciences, Paediatrics and Family Medicine, since ID is presently included within the curricula of these four departments. Complementary additional interviews were conducted with relevant stakeholders within Gauteng

Province, since the headquarters of many of the relevant non-governmental organisations and government departments were located in either Johannesburg or Pretoria.

2.4 Data Collection Procedures and Study Participants

2.4.1 Curriculum Review and Analysis

All curricular material, including lecture notes and prescribed reading materials used during the 2010 and 2011 academic years were reviewed to identify which aspects of the 15 components of the Lennox and Diggens model were covered by the curriculum and to what extent they were covered. Since curricular material is regularly reviewed and changed, and since Wits has recently changed from a Comprehensive 6 year Programme to the Graduate Entry Medical Programme (GEMP), all material identified by the Curriculum Implementers as being the most relevant and applicable from GEMP years 1-4 was reviewed.

Before proceeding, an overview of how the curriculum at Wits is structured is described here so that references in future sections may be understood within a frame of reference. The Graduate Entry Medical Programme (GEMP) refers to the last 4 years of the 6 year medical programme since it accepts both individuals who have a previous appropriate undergraduate degree and those who have entered from high school but have completed two years of undergraduate medical training. The 4 GEMP years comprise mostly of theoretical / knowledge training in GEMP years 1 and 2 and mostly of clinical/ practical training in GEMP years 3 and 4. During these latter 2 years, students rotate in small groups of approximately 5 students each where they are assigned to a particular 'clinical block' e.g. paediatrics for 6 weeks at a time at a tertiary teaching hospital.

Since GEMP years 1 and 2 are largely theoretical, it is worth understanding that teaching is "organ system based", for instance there is a block on the cardio vascular system, a block on the renal system

and so on. These blocks run over a two year period. Within the blocks are themes which run vertically through the years. These include Basic & Clinic Sciences, which comprises about 80% of the teaching and three psycho social themes falling under Family Medicine which include 'Community Doctor', 'Patient Doctor' and 'Personal and Professional Development' themes. Within the organ based system, students work on a particular case each week and these cases include learning topics and theme sessions.

As a result, most of the curricular material analysed stemmed from GEMP Years 1 and 2 due to the significant focus on theoretical knowledge during these years. A data extraction sheet, which focused on the 15 aspects identified in the Lennox and Diggens model, was used to review curricular materials.

2.4.2 Key Informant Interviews with Curriculum Implementers

In order to complement the information obtained from the curricular review, key informant interviews were carried out with Curriculum Implementers. Using a semi-structured interview guide, three members of the teaching staff comprising of the Departmental Head and two of the most appropriate Lecturers or block Teachers (as recommended by the Departmental Head) were purposively selected to participate in the in-depth, face-to-face interviews. The teaching staff members were chosen on the basis of being involved with prescribing the content, the method of teaching and the delivery of the curricula from each of the four departments (Human Genetics, Neurosciences, Paediatrics and Family Medicine). In total, 12 interviews were conducted. The interviews intended to determine the participants' opinions with regard to the content and appropriateness of the curricula offered as well as the materials and methods used to teach medical students. The key questions that were covered included:

- Factors affecting the health of individuals with ID in South Africa including burden of disease, accessibility of health facilities and training of health care professionals

- A description of how the department in question teaches the subject of ID including references to the nature and quantity of training, written reference material for students and examinations on the subject.
- The extent to which the curricular material covered the 15 aspects of knowledge, skills and attitude recommended in the Lennox and Diggens model
- The extent to which the four departments contributed to improving the health status of individuals with ID

2.4.3 In-depth Interviews with Key External Stakeholders

A total of six external stakeholders representing 3 non-governmental organizations, 1 health professional accreditation body and 1 curricular compliance body were purposively selected to participate in the study due to their current involvement in the field of the health of individuals with ID and/ or teaching standards. Snowball sampling approach, which involved asking each key informant to identify others to interview, was used once again.

A semi-structured interview guide was used to assess:

- The role of the stakeholders (their services, successes, challenges) with respect to individuals with ID and/or teaching standards
- Stakeholders' perception of factors influencing the health status of individuals with ID
- Stakeholders' opinion on which organizations or structures would be most influential in improving the health outcomes in individuals with ID.

2.4.4 Focus Group Discussions with Medical Students

Three focus group discussions were conducted with medical students to determine the extent to which the students felt that their degree is preparing them for managing patients with ID. Each focus group consisted of five students: the one group consisted of five 4th (GEMP 2) year students and the other

two groups each consisted of five final year medical students (GEMP 4). The FGD's were conducted after the key informant interviews had been completed as the advice of involving both GEMP 2 and GEMP 4 stemmed from these interviews. The rationale was that GEMP 2 students would be able to reflect most accurately on the theoretical, especially knowledge, aspects of the teaching since it would have been taught to them most recently. Consequently GEMP 4 students would have the hindsight of reflecting back on their entire medical training and would be able to draw on the clinical and practical experiences of their last 2 years most accurately.

The students were recruited following a brief verbal description of the research from one of their lecturers in class and a request for their voluntary participation. All FGD's were held on the Wits campus in between or before classes. Each FGD began with an overview of the study by the interviewer before obtaining consent from each participant and then proceeding with the interview. Due to the rotation of students, final year focus group discussions were held with students rotating through one of the departments involved in the study.

2.5 Data Analysis Plan

All the interviews were digitally-recorded and transcribed verbatim in Microsoft Word. Thematic content analysis was performed on all transcriptions and dominant themes and sub-themes were identified.

The analyses of the key informant interviews from each of the various departments and their corresponding curricular material were merged into the overall analysis. It is at this stage that the analyses of the focus group discussions were included, since the questions and responses from the students were not specific to the blocks that they were on at the time of the interview. Finally, the analyses of the data obtained from the external stakeholder interviews were integrated and the context and possible recommendations were unpacked. Extracts and quotes from interviews, focus group

discussions and curricular material have been included in the overall analysis to validate the findings of this research.

2.6 Data Management and Quality Assurance

In order to ensure consistency, a coding system was applied to both the digital recordings and transcriptions. A key was also kept labeling the interviewee's title and department, date, assigned code and proof of necessary consent forms to ensure that transcriptions were not mixed during the analysis phase. This key also allowed the study to be conducted in a structured manner, ensuring that a log was kept of when the appropriate individuals from each department or stakeholder were identified, interviewed, transcribed and the post transcription checks completed.

All printed interview transcriptions were checked and in some instances corrected whilst listening to the original voice recordings. This post transcription check allowed the reader to ensure that the captured transcription was in fact a true reflection of the interviewee's comments and answers.

The transcriptions and digital recordings remain saved in a soft format on a password encrypted external storage device.

2.7 Ethical Considerations

The proposal was submitted to and approved by the University of the Witwatersrand Ethics Committee for Research on Human Subjects (M10353). Further approval was obtained from the Heads of the four departments engaged in key informant interviews, as well as the Dean of Students, to allow interaction with students during focus group discussions.

All participants received the study information sheet and consent forms including contact details of the study investigators either a few days prior to conducting the interview or FGD, or immediately prior to

the interview. Sufficient time was given to allow the respondent to read all of the study information sheet, interview consent form and digital recording consent form. A verbal account of the research was also given before proceeding and assurances regarding confidentiality and anonymity were emphasized. A unique code was assigned to each individual interviewed and transcripts bore the code and not the name of the individual involved. Participants were also assured that the recordings and transcripts will be destroyed 2 years after submission of the research report. In the case of the FGD's, participants were requested to respect each other's anonymity whilst also emphasizing that anonymity could not be guaranteed in FGDs unless each respondent ensured that the discussion was kept confidential.

All participants submitted signed consent forms for both the interview and digital recording before commencing interviews. All participation was voluntary and no incentives were issued at any stage during the study. Respondents were assured that their responses would not be shared with their managers or supervisors.

All key informant interviews took place in the respondents' offices and in one case in a closed meeting room. FGD's took place in closed tutorial rooms.

CHAPTER 3: RESULTS

3.1 Introduction

In this chapter, the results will be presented according to three main broad sections in response to the study objectives namely: a) analysis of teaching materials and methods; b) assessment of medical training against Lennox and Diggens model and c) perceptions on the appropriateness and adequacy of the training offered to medical students in the field of ID. Each broad section is further divided into sub-sections as shown in Table 2 below.

Table 2: Broad Structure of the Results Section

Broad Theme	Sub-Themes
1. Analysis of teaching materials and methods	• Learning topics and themes sessions • Clinical teaching • Examination methods
2. Assessment against Lennox and Diggens model	• Knowledge aspects across Departments o Knowledge aspect 1: Knowledge about the nature, frequency and causes of intellectual disability o Knowledge aspect 2: Common health and behavioural problems in people with an intellectual disability o Knowledge aspect 3: The impact of an intellectual disability on affected individual and their family o Knowledge aspect 4: Community resources, services and useful medical and non-medical referrals o Knowledge aspect 5: Principles and philosophies of health care for people with an intellectual disability
	• Skills aspects across Departments o Skill aspect 1: Communication with people who are intellectually disabled and their families o Skill aspect 2: Examination, assessment and diagnosis of people who have an intellectual disability

Broad Theme	Sub-Themes
	○ Skill aspect 3: Appropriate referral to and ability to access and liaise with community organisations and specialists ○ Skill aspect 4: Resourcing information from carers and other sources
	• Attitudes aspects across Departments ○ Attitude aspect 1: Treating people with an intellectual disability as equal ○ Attitude aspect 2: Looking beyond the disability ○ Attitude aspect 3: Respect and appreciation of the rights of people with an intellectual disability ○ Attitude aspect 4: Opening up to examining one's own attitudes ○ Attitude aspect 5: Respect for carers' information and opinions ○ Attitude aspect 6: Respect for the wishes and beliefs of people with an intellectual disability and their families
3. Perceptions on the appropriateness and adequacy of the training offered to medical students in the field of ID	• Appropriateness and effectiveness of teaching and examination methods • Appropriateness and effectiveness of clinical exposure • Perceived importance of teaching about intellectual disability • Adequacy of the curriculum on intellectual disability

3.2 Analysis of Teaching Materials and Methods

Based on the curriculum review and interviews with key informants, it was found that Wits used many varied teaching methodologies and draws on significant materials to teach their students. Whilst the field of ID was covered to some degree by all the four departments, the majority of the teaching materials and methods were not specific to ID. Instead, students were taught about disability in general and or a specific pathology that may or may not be associated with ID, such as Epilepsy or Cerebral Palsy. This is highlighted in more detail in the results in the following section.

3.2.1. Learning Topics and Theme Sessions

The interviews with Curriculum Implementers revealed that at the time of the study, Wits did not offer a block, theme or session (e.g. a lecture) specifically on ID and none of the prescribed reading materials or textbooks were specific to the subject of ID. However, two departments, namely Paediatrics and Human Genetics, prescribed textbooks with some relevance to ID. For instance, the Department of Paediatrics prescribed a book by H. Coovadia entitled "Coovadia's Paediatrics and Child Health", 6th Edition' while the Department of Human Genetics prescribed a report by Christianson and colleagues entitled "March of Dimes Global Report on Birth Defects". The former contained limited information, (approximately 4 pages) specific to intellectual disability whilst the latter includes extensive information on ID in the context of birth defects.

Despite ID not being taught as a specific learning topic, aspects directly and indirectly related to ID were included within the following Learning Areas:

Learning Area (Theme)	**ID Related Session**
Biopsychological ("Life on the street" block)	Communication skills between the Dr and patient
Chronic Illness (Endocrine Block)	Stigma and labeling
Disability (Musculoskeletal Block)	Living with disability
Case-Related (Neurosciences Block)	Impact and experience of Epilepsy

Source: derived from University of the Witwatersrand Faculty of Health Sciences, GEMP Themes, 7th edition, 2011

Within these learning areas, a number of teaching methodologies were used including the use of audio-visual PowerPoint presentations, real life and simulated case studies followed by discussions, debates and guest lecturers by specialists on a particular topic. Some written materials aside from the aforementioned textbooks were also distributed supporting the aforementioned methodologies eg lecturer handouts and written case studies .

Within the Learning Area of Disability, it is worth highlighting that this learning topic was supplemented with a case study of a Down Syndrome patient. This was used to stimulate debate around aspects pertaining to knowledge, skills and attitude related to an ID patient. Also within this Learning Area, a guest lecturer with cerebral palsy but without ID was invited for a session to provoke debate and challenge attitudes and stereotypes towards the disabled.

3.2.2. Clinical Teaching

Clinical Teaching is mostly limited to GEMP Years 3 and 4 and it is practical, rather than theoretical. The Curriculum Implementers mentioned two facets of Clinical Teaching which were relevant to teaching students about ID:

- *Bedside teaching*: Both planned and opportunistic teaching of a patient (mostly children) with ID were noted as being applied in the Paediatrics and Neurosciences Departments. Opportunistic bedside teaching most often occurred when the patient case was complicated or unusual and was thus used for teaching purposes.
- *Clinical patient management*: Within the Departments of Human Genetics, Paediatrics and Neurosciences, medical students were required to observe, treat or counsel patients and their families and these patients sometimes had an intellectual disability.

The Clinical Teaching described above was influenced by the students' rotations to clinical blocks at different hospitals. Different teaching methods were applied at different academic hospitals and thus the students' clinical rotation determined their learning opportunities. Not all students rotated through all academic hospitals or clinical settings and coverage of ID differed significantly from one hospital to the other. In addition, teaching was affected by the in-patients present at the time of the students' rotation, thus the practical training that the student would be exposed would be affected not only by the clinical rotation /teaching hospital but also by the patients admitted at the time of rotation.

3.2.3. Examination Methods

There was consensus between focus group participants and Curriculum Implementers that examinations were key determinants of whether or not a student retains knowledge on the subject of ID. However, none of the curriculum Implementers described the inclusion of questions on the subject of ID as mandatory in examinations; and when included, students may choose to omit answering them. Nonetheless, the Department of Human Genetics reported including questions regarding managing a patient with ID in previous examinations. During their Paediatrics block, final year students also commented on having completed an Objective Structure Clinical Exam (OSCE), which is a compulsory clinical examination on a patient with cerebral palsy including an intellectual disability. These participants felt that the exam forced them to study the relevant subject matter and resulted in them feeling more confident to treat a patient with ID in future.

3.3. Assessment of medical training against the Lennox and Diggens Model

This section of the results is intended to show the extent to which training of medical students met the key features of the 15 aspects of Lennox and Diggens framework. Although some of these aspects overlap, each is elaborated below for the sake of clarity.

3.3.1 Knowledge Aspects across Departments

Table 3 summarizes the five knowledge aspects outlined in the curriculum and the extent to which they are taught across the four Departments. It is apparent that three of the five aspects (nature, frequency and causes of ID; impact of ID on the individual and their family; community resources, services and useful medical and non-medical referrals) were covered thoroughly by at least three departments. The curricular review and interviews with Curriculum Implementers demonstrated that the Human Genetics Department covered the knowledge aspects the most comprehensively, relative to the other Departments, considering that four of the five aspects were thoroughly taught in this

department (Table 3). The two Departments that covered the knowledge aspects the least were Neurosciences and Family Medicine.

Table 3: Overview of the Knowledge Aspects across Departments

Knowledge Aspects				
	Human Genetics	Paediatrics	Neurosciences	Family Medicine
Nature, frequency and causes of ID.	2	2	1	0
Common health and behavioural problems	2	1	1	0
Impact of ID on the individual and their family	2	1	1	2
Community resources, services and useful medical and non-medical referrals	2	2	1	1
Principles and philosophies of health care for people with ID.	1	0	0	1

Key		
0 = Not covered at all within the curriculum	1 = Partially covered within the curriculum i.e. Only 1 sub-component is included in the teachings	2 = Thoroughly covered within the curriculum i.e. All sub-components are included in the teachings

3.3.1.1 Knowledge Aspect 1: Knowledge about the nature, frequency & causes of intellectual disability

The findings show that at least two Departments, Human Genetics and Paediatrics extensively covered the nature, frequency and causes of ID. This finding is supported by Curriculum Implementers from these two departments who described their teaching as including aspects of causes, prevalence and care.

> "*We give a tutorial on birth defects – definitions, epidemiology, aetiology, patho-physiology, clinical aspects, care."* (Lecturer 1, Human Genetics Department)

> *"We give a tutorial on an approach to developmental delay and that's intellectual disability. What are the causes? How do you manage it? How do I approach it?"* (Lecturer 3, Paediatrics Department)

In addition, the Paediatrics Department included some South African-specific statistics, such as those for Foetal Alcohol Syndrome, within the Knowledge Aspect 1 lectures. This is relevant considering that South Africa has a very high prevalence of Foetal Alcohol Syndrome.

Regarding the Neurosciences Department, which partially covered this aspect, it was found that although the definition, differential diagnoses and detailed explanation on the levels of ID were included in the lecturer notes, the prevalence/frequency and causes of ID were not mentioned. One curriculum implementer in the Neurosciences Department commented on how the teaching includes information on the nature of ID and its clinical assessment:

> *"In Neurology block, one lecture with Child Psychiatry discusses the different levels of intellectual disability and Dyslexia and learning disorders, how you approach them, how they might present clinically" (*Lecturer 2, Neurosciences Department).

Family Medicine on the other hand, was the only department that did not make any reference to the nature, causes or frequency of ID.

3.3.1.2 Knowledge Aspect 2: Common health and behavioural problems in people with an intellectual disability

The Human Genetics was the only Department that covered this aspect extensively. To illustrate this, a fictional but plausible case study presented to students in this Department involving a Down Syndrome patient and her mother described some of the typical health problems experienced by Down Syndrome patients:

> *"We were told that she was at a greater risk of heart defects, hearing problems, eye problems, learning difficulties…"* (Prescribed Case Study, Human Genetics Department)

This information was corroborated by one of the curriculum implementers who highlighted the cardiac conditions prevalent in some ID patients:

> *"I go through a whole series of exercises of what a Doctor can do for example; a child with Trisomy 13 [a chromosomal condition associated with severe intellectual disability and physical abnormalities in many parts of the body]. Even if they [the doctors] don't make the diagnosis of Trisomy 13, the child may have an airway problem or a heart defect which has to be treated"* (Lecturer 1, Human Genetics Department).

The Paediatrics and Neurosciences Departments partially covered this aspect while the Family Medicine Department did not cover it at all. The Paediatric teaching was limited to behavioural problems and Epilepsy:

> *"Behavioural problems may require special behaviour modification therapy or medication. Anti-epileptic drugs may be prescribed where appropriate."* (Coovadia 2009; Prescribed Book; Paediatric Department)

The interviews with the curriculum implementers in the Paediatrics Department and focus group discussions with students further suggested that various associated health disorders and their prevention were taught in this Department:

> *"For instance we learnt in Paediatrics that with Down Syndrome, there are co-morbidities associated with it so you have to exclude any cardiac abnormalities. Also the patients normally can't take care of themselves so there's the issue of hygiene and infection."* (Focus Group 2, Final Year Medical Students)

In the Neurosciences Department on the other hand, concurrent emotional or behavioural problems were referenced, whilst details were also provided on associated disorders such as language and learning disorders and Epilepsy. An example of this was narrated by the curriculum implementer:

> *"As they are psychiatrically related, I talk about the high incidence of depression and anxiety and that kind of thing"* (Lecturer 3, Neurosciences Department).

3.3.1.3 Knowledge Aspect 3: The impact of an intellectual disability on the individual and on his/her family

The two Departments that covered this aspect extensively were the Human Genetics and Family Medicine Departments. In ensuring that the students grasped the aspect on the impact of intellectual disability effectively, the Human Genetics Department used case studies and guest appearances of parents with ID children as the learning tools:

> *"We bring in two mums who've got a child with Down Syndrome who've had very different experiences and they talk about their experience being in the community with a child with an intellectual disability."* (Lecturer 3, Human Genetics Department)

This finding was supported by a participant from a focus group with 4th year medical students who recalled how the lecture demonstrated the impact that a disability has on a family:

> *"A lady with a Down Syndrome child came to speak to us. She struggled with getting her into school and how the disease or the syndrome affected her family."* (Focus Group 1, 4th year medical students)

During the focus group discussions, the participants also recalled how the parent in the Case Study expressed the emotional impact and stigma associated with having a child with intellectual disability:

> *"Having a child that has Down Syndrome was a shock. There is no doubt that there is an extra level of stress. There has also been some difficulty in our family. My mother insisted that the news of the diagnosis should not reach some members of our family."* (Prescribed Case Study, Human Genetics Department)

Like Human Genetics, the Family Medicine Department also used affected individuals as guest speakers in their lectures on "Living with a Disability" and "The family of a child with Epilepsy". Although not specific to ID, in these sessions, students observe as the patients are interviewed and encouraged to speak about their experiences of illness and disability:

> *"She's Cerebral Palsied herself and in a wheelchair. She workshops the whole class and it is really awareness-raising about the struggles and the needs and dignity of disabled people"* (Lecturer 2, Family Medicine Department).

The Paediatrics and Neurosciences Departments on the other hand, partially covered this aspect on the impact of disability. One of the curriculum implementers in the Paediatrics Department did however emphasize that the importance of listening to the families affected by ID and addressing their needs is taught, thus allowing students to gain an understanding of the burden experienced by families of children with ID:

> *"My first thing that I teach them is that the most important thing that they've got to know is what the parents want from you. If you do nothing else but answer what the parents want from you, your job is done"* (Lecturer 3, Paediatrics Department).

This lecturer also referenced her teaching on the impact of living with a disability:

> *"I give examples of the sort of problems that people would have at various stages of their lives with the different mental handicaps"* (Lecturer 3, Neurosciences Department).

3.3.1.4 Knowledge Aspect 4: Community resources, services and useful medical and non-medical referrals

There are two aspects within the Lennox and Diggens model which are similar and these are, "Knowledge of community resources, services and useful medical and non-medical referrals" and "Skills pertaining to the appropriate referral to, and ability to access and liaise with, community organizations and specialists". In order to differentiate between these two, the latter was interpreted as practical teachings where students witnessed and/ or demonstrated the relevant skills. The knowledge aspect therefore was interpreted as theoretical, didactic teachings in which the students were for instance taught which community resources are relevant, but were not shown how to access them. It is also important to note that 'community resources and services', was interpreted by the respondents as services such as disability grants, support groups for parents (for example those formed by NGO's such as Autism SA, Down Syndrome SA, Fragile X Association), special schools, crèches catering for young children with ID, protective workshops and adult care centres for people with ID.

Given this interpretation, the results showed that the Human Genetics and Paediatrics Departments were the two Departments that covered this aspect most thoroughly, however some teaching of the subject was noted across all four departments.

A significant emphasis within the teaching of most departments was placed on medical referrals to allied healthcare professions and the importance of the multidisciplinary approach. This was especially evident in the March of Dimes Report from the Human Genetics Department.

> *"Habilitation for people with birth defects through neurodevelopmental therapy – speech, occupational and physiotherapy – are an important component of treatment that can reduce levels of disability."* (Christianson 2006, Prescribed Book, Human Genetics Department)

This prescribed reading material was supported by didactic teachings which added the importance of the multidisciplinary team, referral for counseling and psycho social support to the habilitation protocol:

> *"We're always emphasizing a multidisciplinary approach, that it isn't even just from a medical point of view, that there is always social workers etc. to be involved"* (Lecturer 2, Human Genetics Department).

> *"I give tutorials on the therapies – OT [occupational therapy], speech [therapy] etc and counseling with psycho social support"* (Lecturer 1, Human Genetics Department).

The prescribed reading from the Paediatrics Department also emphasized the importance of counseling, but interestingly it brought up the aspect of social benefits and community workers too:

> *"Counsel parents about the condition and about social benefits available. The need for genetic counseling may be of particular relevance here….Community workers specifically trained in this field can be of tremendous support to the family. The younger the child, the more effective the therapy will be."* (Coorvadia 2009, Prescribed Book, Paediatrics Department).

The aspect of social benefits / disability grants was not only mentioned in the literature but was actively taught to the students by the Paediatric and Family Medicine Departments. This was reflected by students in a focus group discussion who recalled the teaching:

> *"It was in Paediatrics and Public Health (Family Medicine) that we were taught about disability grants for people with disabilities"* (Focus Group 3, Final Year Students).

As is evident under the teaching of Skills Aspects described later in this report, the Paediatric Department included both theoretical and practical teachings on community resources, NGO's and support groups. The students reflected on the fact that they had been taught specifically on the role of support groups in patient care:

> *"We've been told about support groups" (*Focus Group 3, Final Year Students).

Finally within the Neurosciences Department, '*referrals to occupational therapy, speech therapy, remedial teaching and management of co-existing medical conditions and the importance of early intervention*' were outlined within the lecture notes. These lecture notes were supported by practical teachings in which students were taught the skills of identifying and liaising with the relevant medical and non-medical resources linked to the patient.

3.3.1.5 Knowledge Aspect 5: Principles and philosophies of health care for people with an intellectual disability

Of all the five knowledge aspects, it is apparent from Table 3 above that the principles and philosophies of health care for people with ID was the one area that was the most neglected across the departments. This aspect was only covered partially by two Departments, Human Genetics and Family Medicine. Eventhough the Human Genetics teaching material described this aspect, its reference was generally aligned with all birth defects, and not necessarily intellectual disability specifically:

> *"The care of patients with birth defects is challenging. All people with birth defects, and their families, are entitled to expect the best possible patient care available to them in their circumstances."* (Christianson 2006, Prescribed Book, Human Genetics Department)

Similarly, in the Family Medicine Department, the aspect of health equity was covered very generally in the lecture notes, but no reference was made to individuals with ID or other marginalised groups.

This was corroborated by a statement made by one of the curriculum implementers who described the focus on policies that orientate services to communities of need:

> *"We focus on health promotion and look at community involvement, policies and re-orienting services and the whole issue around principles of primary health care in community development"* (Lecturer 3, Family Medicine Department).

Both the Paediatrics and the Neurosciences Departments did not cover this aspect at all.

3.3.2. Skills Aspects across Departments

Table 4 below illustrates broadly the four skills aspects outlined in the curriculum, demonstrating that all the sub-components of all the skills aspects were taught because at least two departments have each aspect thoroughly covered and no skill is omitted. The Paediatrics and Neurosciences Departments fared the strongest overall in this section as they each covered 3 of the 4 skills components thoroughly, whilst the Department of Family Medicine demonstrated that they were not intimately involved in teaching the skills aspects.

Table 4: Overview of the Skills Aspects across Departments

Skills Aspects				
	Human Genetics	Paediatrics	Neurosciences	Family Medicine
Communication with people with ID and their families	2	1	2	1
Examination, assessment and diagnosis of ID	1	2	2	0
Appropriate referral to and ability to access and liaise with community organisations and specialists	0	2	0	2
Resourcing information from carers and other sources	1	2	2	0

Key		
0 = Not covered at all within the curriculum	1 = Partially covered within the curriculum: Only 1 sub-	2 = Thoroughly covered within the curriculum: Both / all sub-

	component is included in the teachings.	components are included in the teachings.

3.3.2.1 Skill Aspect 1: Communication with people who are intellectually disabled and their families

Both Human Genetics and Neurosciences Departments provided a thorough teaching on this subject whilst Paediatrics and Family Medicine by comparison only touched on the subject. The prescribed case study by the Department of Human Genetics clearly addressed the aspects of sensitivity, privacy and objectivity by depicting the impact of poor communication skills via a parent's story:

> "*We really should have been told in private. The nurse at the time failed to appreciate the importance of delivering the information sensitively*." (Prescribed Case Study, Human Genetics Department).

It was apparent from the Curriculum Implementer that these communication and counseling skills were also taught to the students in subsequent lectures:

> *"The students have to be able to give basic counselling and break bad news and understand the role of counselling and psychosocial support"* (Lecturer 1, Human Genetics Department).

The Paediatrics Department demonstrated the importance of communication with families, as one curriculum implementer described the teaching in the clinical setting:

> *"In the clinic, when we do see patients we do discuss and try to show the emphasis of counselling, especially prognosis of outcomes"* (Lecturer 2, Paediatrics Department).

Despite this teaching, the students did not feel that they had been taught specifically how to communicate with a patient with ID:

> *"You might get a Doctor saying to you, 'try this or try that,' but nobody has specifically told us the way to approach people with ID"* (Focus Group 3, Final Year Students).

It was apparent that within the Neurosciences Department, communication with ID patients and their families was taught to the students as an intervention or treatment skill. Emphasis was placed on communication and counselling with particular reference to managing the conflict that arises as a

result of the intellectual disability. As an example, the lecture notes suggest opening the dialogue by beginning to identify areas that need interventions:

> "*Identify areas that need intervention such as conflict with parents over homework or parental accusations that the child is slow*." (Prescribed Lecture Notes, Neurosciences Department)

The Curriculum Implementer supported the finding that these skills were taught, but with little description on the depth of the teaching:

> *"Communication with the family or the patient is included"* (Lecturer 1, Neurosciences Department).

Communication, especially with patients, was specifically taught within the Family Medicine Department both theoretically and practically. The teaching however did not involve a patient with any form of disability and thus failed to fully meet the objective that Lennox and Diggens described. A curriculum implementer described the teaching process as follows:

> *"We get them to actually practice the communication skills which they had a lecture on, so they have to go to the ward and identify a patient and conduct a conversation*" (Lecturer 2, Family Medicine Department).

3.3.2.2 Skill Aspect 2: Examination, assessment and diagnosis of people who have an intellectual disability

There are three sub-components, (examination, assessment and diagnosis) within this aspect, of which the Paediatrics and Neurosciences Departments covered all three. These were included within the prescribed reading material and clinical teaching:

> *"A thorough clinical examination is essential. Dysmorphic features might suggest a chromosomal abnormality or hypothyroidism. It is imperative that the hearing is assessed. It may be difficult to determine the degree of MR (Mental Retardation) in a young child and a firm prognosis should be avoided."* (Coovadia 2009, Prescribed Book, Department of Paediatrics,)

This didactic teaching was followed by practical teaching as described by a Paediatrics Curriculum Implementer who emphasized that the students were taught what constitutes normal development and are thus able to recognize and diagnose delayed development:

> *"We teach them neurology assessment including the child's development and scholastic capabilities. We give them cases and expect them to identify developmental delay"* (Lecturer 2, Paediatrics Department).

The teaching offered by the Neurosciences Department appeared to be as comprehensive as that offered by Paediatrics as it included assessing the clinical picture and administering standard tests, for example Intelligence Quotient (IQ) tests. The emphasis in the practical teaching however was placed on the clinical assessment and resulting diagnosis:

> *"The training is based on the clinical picture, that you're going to be able to assess somebody along the lines of how they present and interact, that you can define the features, that you understand what the condition is about and how to diagnose the candidate"* (Lecturer 1, Neurosciences Department).

Although the Department of Human Genetics also covered all of the three sub-components (examination, assessment and diagnosis), it was noted that the focus was mainly on identifying genetic conditions, neglecting a significant proportion of conditions associated with ID:

> *"They have to be able to recognize and diagnose genetic birth defects – basic recognition and diagnosis for basic problems"* (Lecturer 1, Human Genetics Department)

No aspect of clinical assessment or diagnosis of ID is covered within the Family Medicine Department.

3.3.2.3 Skill Aspect 3: Appropriate referral to and ability to access and liaise with community organisations and specialists

The two components within this aspect namely the medical component of specialist referral and the non-medical components of community organizations, were both addressed within the Paediatrics and Family Medicine Departments. Both of these Departments either allowed the students to directly observe the liaison with community organizations or specialists or to do so themselves, satisfying the requisite skill transfer, rather than only knowledge transfer. It was not apparent from the teachings that

the Departments of Human Genetics and Neurosciences actively taught the students practical skills on appropriate referrals for patients with ID, although discussions and the transfer of knowledge on referrals were included as a finding previously in this report.

Although not specific to ID, the Family Medicine Department depicted that the skills of accessing alternative and non-medical services was taught during their Integrated Primary Health Care Block. This is a teaching period in which students are based at a community health facility and are taught to apply their knowledge practically:

> *"When you get in to a department or an institution, then you learn about how to refer. When I was placed at a rural institution, we were taught while we were there, but it is different for every institution"* (Focus Group 2, Final Year Students).

During this 'Block' the students were required to conduct a project which they presented at the end of their rotation, clearly demonstrating that they had learned the skill of accessing and liaising with appropriate organizations and health facilities:

> *"One of the requirements of their project or their presentation is that they must know what community resources are available to them....They need to know about some of the special facilities, support groups and all the rest of it"* (Lecturer 2, Family Medicine Department).

> *"The GEMP3 students have to do an ecomap which is about mapping the health facilities and other facilities around you which are available for referral"* (Lecturer 1, Family Medicine Department).

In the Paediatrics Department, both knowledge and skills training were included in the curriculum with the latter being both by observation and engaging with appropriate allied healthcare professionals. The students rotating through the Paediatric Block at Charlotte Maxeke Hospital for example were taught about the specific clinics and support groups that were available within that geographic area and they witnessed the important role that specialist organizations and community groups play:

> *"The students experience the different clinics and support groups for Down Syndrome, Autism, Epilepsy, Neuromuscular etc. They see speech therapy forming a parent support group and they see us bringing in someone from Autism South Africa who can hand out literature and help with resources which is more than we as Doctors can provide"* (Lecturer 3, Paediatrics Department).

This statement was supported by final year students who reflected on the liaison that they had with the patient's therapist and parent:

> *"In paediatrics, we used to engage in family meetings or with the Occupational Therapist and we would have small discussions with the mother of the child with ID along with the Occupational Therapists."* (Focus Group 2, Final Year Students)

3.3.2.4 Skill Aspect 4: Resourcing information from carers and other sources

As Lennox and Diggens do not define 'Resourcing information from carers and other sources' in their research, it was understood by the researcher to mean 'gathering information from those who have direct or indirect contact with the patient and are able to contribute relevant information regarding the patient's care'. Of the four departments, Neurosciences and Paediatrics were again found to cover this aspect most thoroughly. They referenced the process for determining the various sources of information on patients aside from only the information from their carers. The other two departments only referenced either the family or alternative sources and were thus not deemed to have thoroughly covered this aspect.

The Neurosciences Department covered this aspect during their teachings on assessing patients. In addition to getting information about ID patients from carers, lecture notes from this Department also mentioned other sources such as telephone interviews with teachers and a review of family records:,

> *"To determine underlying reasons for school refusal, the assessment should include conducting direct or phone interviews with teachers; family records from pre-school onwards."* (Prescribed Lecture Notes, Neurosciences Department)

A curriculum implementer from the Neurosciences Department also described how the skills for accessing such information was taught to the students in case studies and in the clinical setting:

> *"The approach is a very integrated one so it's an approach to the distressed child. The students have got to read that and tease out what is intellectual disability, what is trauma, what is abuse, what is anxiety"* (Lecturer 2, Neurosciences Department).

Given the focus on genetic causes of ID within the Human Genetics Department, the course material only covered this aspect with respect to accessing information thoroughly from family members. This focus was described by a Curriculum implementer who emphasized the importance of developing a comprehensive history of the patient and his family in order to fully understand the patient's situation: *"They [the students] are trained to take a history – birth history, family history, social history, past history from the patient or their family ."* (Lecturer 1, Human Genetics Department).

Through tutorials, students on rotation in the Paediatrics Department were taught to access information from carers and other members of the multidisciplinary medical team by observation and participation:

> *"When I'm with a family, the most important person is the family. The students are there as part of the process and they can observe how I talk to the patients and families."* (Lecturer 2, Paediatrics Department)

> *"After the Neuro Developmental Clinic, the whole team gets together to discuss the patients so there's that multidisciplinary approach."* (Lecturer 2, Paediatrics Department)

The Family Medicine Department showed no reference of teaching students the skills to access information regarding a patient from carers or other sources aside from the reference to communicating with patients mentioned previously.

3.3.3 Attitude Aspects

It is apparent from Table 5 below that the attitude aspects outlined in the Lennox and Diggens model were taught to a far lesser degree than those of knowledge and skills. Four of the six attitudinal aspects were taught thoroughly by at least one department, Human Genetics, whilst the Paediatrics and Neurosciences Departments least addressed attitudinal issues in their teachings. It is also interesting to note that almost all departments did not address the aspect of respect for carers' information and

opinions with the exception of the Family Medicine Department which partially addressed it. In addition, the aspect on respect and appreciation for the rights of people with ID was also least covered and was only partially covered by Human Genetics and Family Medicine Departments.

Table 5: Overview of the Attitude Aspect across Departments

Attitude Aspects				
	Human Genetics	Paediatrics	Neurosciences	Family Medicine
To treat people with ID as an equal	2	0	0	1
To look beyond the disability and see the person first	2	0	0	1
To have respect and appreciation of the rights of people with an ID	1	0	0	1
To be open to examining one's own attitudes	2	0	0	2
Respect for carers information and opinions	0	0	0	1
Respect for the wishes and beliefs of people with ID and their families	2	1	2	2

Key		
0 = Not covered at all within the curriculum	1 = Partially covered within the curriculum i.e. some reference is made but not in the context of ID	2 = Thoroughly covered within the curriculum i.e. significant teaching on the subject with or without reference to ID

3.3.3.1 Attitude Aspect 1: To treat people with an intellectual disability as equal

This aspect was only addressed by two Departments, namely Human Genetics and Family Medicine with the latter providing a very broad teaching out of the context of ID or disability generally.

The Department of Human Genetics addressed the aspect of equitable treatment within the case study prescribed to the students as can be illustrated by this extract in which the parent of a child with ID describes the way in which health care professionals should treat her child:

> *"We have an excellent general health visitor. She keeps in contact and compares my child to any other, giving an honest opinion. That's what we have asked for."* (Prescribed Lecture Notes, Human Genetics Department)

Additionally the Curriculum Implementer described how the equality and dignity of patients with ID was emphasized during the teachings:

> *"They are taught that children with birth defects are entitled to every aspect of human dignity, including the human dignity that they're required to have as a patient coming in with a disability, a patient with Cancer, the common cold or anyone else"* (Lecturer 1, Human Genetics Department).

Within Family Medicine, this aspect was not referenced in the course material, however both the Curriculum Implementer and 4th year medical students reflected back on a theme session in which a cerebral palsy adult without an intellectual disability addressed the class about the importance of connecting with the person with the disability:

> *"To me the most instructive was when she said 'Speak to me, you can speak directly to me and not to my caregiver*" (Focus Group 1, 4th year Student).

This attitudinal aspect was not covered by teachings within the Paediatrics or Neurosciences Departments.

3.3.3.2 Attitude Aspect 2: To look beyond the disability and see the person first

Similar to the aspect described above, the Department of Human Genetics placed significant emphasis on teaching this aspect whilst the Department of Family Medicine used a specific example, but provided generic teachings and lessons from it.

Within Human Genetics, this aspect was included as part of a case study discussed with the students in which the mother of an ID child made the point about being treated as an individual, not a medical condition:

> *"I see no point in mentioning that she has Down Syndrome as to me it is a label with a terrible stereotype. I want them to see her for who she is."*(Prescribed Lecture Notes, Human Genetics Department)

This same point was further emphasized by a curriculum implementer as being highlighted during lectures with the students:

> *"I make it quite clear that children with birth defects are people, they are not something different, which is how they are perceived, they are people. First, foremost and always, they are people"* (Lecturer 1, Human Genetics Department).

Although this aspect was not referenced in the reading material from the Family Medicine Department, the Curriculum Implementer mentioned the same guest lecture that the students referenced previously and the important lesson about dignity that she taught the students:

> *"She's physically disabled but she's brilliant in getting the students to understand that you're talking to another person"* (Lecturer 2, Family Medicine Department).

Despite the guest speaker not having ID, the focus group participants felt that they had understood the principle of always treating their patients as people and not letting the disability or clinical features monopolize their approach:

> *"In terms of applying the principle, we're taught that you must always acknowledge that the person is there, even if it is just to say hello and ask how they are"* (Focus Group 1, 4th year students).

This attitudinal aspect was not covered by teachings with the Paediatrics or Neurosciences Departments.

3.3.3.3 Attitude Aspect 3: To have respect and appreciation of the rights of people with an intellectual disability

Both the Departments of Human Genetics and Family Medicine touched on the aspect of appreciating the right of people with ID, but neither referenced what those rights were and thus neither were found to address this aspect thoroughly.

The Department of Human Genetics did not reference rights specifically in the course material, however entitlement to the *"best care available in their circumstances"* (Christianson, 2006) was emphasized in the March of Dimes Report. This right was supported by teachings of respect for a patients individuality by a Curriculum Implementer:

> *"We teach them to fully inform your patients, support the patients in their decision making. Those are specific attitudes that we teach and that they observe"* (Lecturer 2, Human Genetics Department).

Within Family Medicine, this aspect was referenced in the written material and in the lectures. The written notes clearly displayed the importance of respect, dignity and equality in dealing with all patients, whilst the students recalled the emphasis placed on respecting human and patient rights in their lectures:

> *"Respect for the dignity of patients and their families that encompasses without prejudice, diversity of background and opportunity, language, culture and way of life" (*Prescribed Lecture Notes, Family Medicine Department)

> *"They talk about rights in health care, about people having the right to seek health care"* (Focus Group 1, 4th year students).

This attitudinal aspect was not covered by teachings with the Paediatrics or Neurosciences Departments.

3.3.3.4. Attitude Aspect 4: To be open to examining one's own attitudes

Both the Department of Human Genetics and Family Medicine addressed this aspect thoroughly whilst the Departments of Neurosciences and Paediatrics did not address it at all.

Within Human Genetics, this aspect was covered on more than one occasion within the prescribed case study. The objective of the theme session involving the case study was to demonstrate that the opinions and attitudes that one holds, might affect the type and level of care that one offers:

> *"Recognizing that personal values and beliefs may influence the care and support provided to clients"* (Prescribed lecture notes, Human Genetics Department).

This teaching was also achieved by discussing the feelings portrayed by the parent of the Down Syndrome child in the case study:

> *"Once the consultation is over they seem to feel the need to make some comment. One implied that I should have had prenatal testing and then had a termination. The other appeared pitying. We have already left one GP practice because of their attitude."* (Prescribed lecture notes, Human Genetics Department)

The impact of the teaching of the personal beliefs the students held was reflected by a curriculum implementer:

> *"In the session the mums were saying, 'Be careful of what you say. This is how I was told my child had Down Syndrome.' And all the students are going, 'Oh!*" (Lecturer 1, Human Genetics Department).

The personal development theme within Family Medicine entitled *'Knowing yourselves – your aspirations and your values and your medical and social culture'* (Prescribed Handbook, Family Medicine Department) provided a thorough teaching on this aspect. It was implemented not only as didactic teaching, but also practical role-playing in which the students were taught to examine the beliefs that they hold:

> *"I do exercises of self-knowledge where you give them a scenario and say, 'how would you react in this situation?' They debate it and we try to examine 'when you express an opinion like this, where do you think it comes from?"* (Lecturer 3, Family Medicine Department).

This attitudinal aspect was not covered by teachings with the Paediatrics or Neurosciences Departments.

3.3.3.5 Attitude Aspect 5: Respect for carers' information and opinions

This aspect was the most under-taught within the attitudes section as it was only taught within the Department of Family Medicine in a generic fashion.

This aspect was covered under teachings within the sub themes of 'Bioethics' and 'Personal Development' within the 'Personal and Professional Development' theme of Family Medicine. The specific objective within this theme depicted below demonstrates that the importance of honesty and compassion in dealing with carers of the patient was taught to the students:

> *"Integrity in all dealings with patients, their families, colleagues and other members of society"* (Prescribed Handbook, Family Medicine Department)

A curriculum implementer emphasized that in teaching the above objective, students are taught to consider and respect the different values and opinions that their patients and their relatives might hold:

> *"It is very much about trying to get the students to understand what their values are and understand that different people have different values"* (Lecturer 1, Family Medicine Department).

The Departments of Neurosciences, Human Genetics and Paediatrics did not address the aspect of carers specifically, but rather those of family members as is described in the section below.

3.3.3.6 Attitude Aspect 6: Respect for the wishes and beliefs of people with an intellectual disability and their families

Of all the attitudinal aspects, this was the most thoroughly taught as it was comprehensively addressed by three of the four Departments.

The Department of Human Genetics described the importance of considering the needs and wishes of the patient within the prescribed literature, March of Dimes Report, although it was specific to birth defects:

> *"Taking into account parent/patient needs can help ensure that services for the care and prevention of birth defects are appropriate, accessible and user-friendly. They can also allow patients and their families to make informed choices and derive maximum benefit from genetic information."* (Christianson, 2006, Prescribed Book, Human Genetics Department)

There was a sense from more than one Curriculum Implementer that an emphasis was placed on teaching students to be respectful of the needs of others by having them sit in on counselling sessions between a lecturer and a patient:

> *"We expect them to observe us counselling and understand the attitude and the perceptions of how you care and manage a patient with a birth defect and their family. It's difficult to assess, but there is a very clear attempt to teach that"* (Lecturer 3, Human Genetics Department).

Although there was no reference to aspects of attitudes in the written material or paediatrics textbook prescribed to students, a Paediatrics Lecturer did highlight that this aspect was touched upon by emphasizing the role of the parent of a child with a disability:

> *"We teach the students that in fact parents know more than Doctors about their child's development"* (Lecturer 3, Paediatrics Department).

Within the Neurosciences Departments, the Curriculum Implementers did not emphasize that this aspect was covered specifically, however the lecture notes did demonstrate that there was teaching on ensuring that the affected child's opinion was prioritized and respected:

> *"During assessment, conduct a child interview about how they see the problem."* (Prescribed Lecture Notes, Neurosciences Department)

The principles of this aspect were covered within the material on personal and professional development within the Family Medicine Department. It was described as important to prioritize the needs of the patient rather than those of the medical practitioner:

> *"The need to always put the patient's interest before one's own."* (Prescribed Handbook, Family Medicine Department)

This was supported by the Lecturer of this particular subject, who said that students should take their time to understand the circumstances of their patient, before advising them on the appropriate care or treatment:

> *"We teach them the principles that they should see each patient as unique with unique needs and that they mustn't come up with assumptions"* (Lecturer 3, Family Medicine Department).

A student within a focus group discussion reflected on how they were taught to appreciate the needs and opinions of the family members, although she could not accurately recall which department the lecture fell under:

"In the beginning of our training, quite a few families came on a day and spoke to us and they had children with Down Syndrome and they basically explained it to us from their point of view – what they go through, how their children are. They gave a different perspective, if you have never been around somebody who has an intellectual disability, and helped to see it from the families' side" (Focus Group 3, Final Year Students).

3.4 Perceptions on the Appropriateness of the Training offered to Medical Students in the Field of Intellectual Disability

3.4.1 Appropriateness and Effectiveness of the Training

Interviews with curriculum implementers revealed that although clinical observation was a widely used teaching method in the Human Genetics, Paediatrics and Neurosciences Departments, it was unclear whether it was an effective means of teaching. Examples of the use of this methodology include teaching aspects of care, counselling, communication and attitudes as illustrated below:

> *"When they're in GEMP3 [5th year] and they're observing counselling, a lot of what we're expecting them to understand is the attitude and the perceptions and how you care and manage the situation, but it's difficult to assess whether they've got that across."* (Lecturer 2, Human Genetics Department).

This was further complicated by the fact that often it was the attitude aspects that are taught through these observation techniques and the student's understanding of the attitudes was difficult to assess in the conventional written examinations used in the GEMP Years 1 and 2:

> *"Attitudes are a little bit harder to assess. It gets easier when you get to the clinical years but we [Human Genetics Department] don't have any role in assessment in the clinical years" (*Lecturer 2, Human Genetics Department).

A facet relating to the inappropriateness of the examination methods was raised independently by all three key informant interviewees in the Human Genetics Department and confirmed by a stakeholder from the Centre for Health Sciences Education. The examinations are set such that students may choose to leave out answering whole sections, since it is not compulsory to answer every section. This means that students can, and sometimes do fail to learn and complete examination sections which relate to intellectual disabilities:

> *"Our consideration at the present time is that the students know that they don't actually have to learn medical genetics to be able to pass their exam so therefore they don't put a lot of effort in to it"* (Lecturer 1, Human Genetics Department).

This is particularly relevant when one reflects on the previous chapter and the proportion of knowledge, skills and attitudes that are taught and examined by this particular department.

In relation to clinical exposure, there were two areas in which curriculum implementers and/or students felt that the teaching methods were not the most appropriate or effective. The first relates to the lack of planned practical exposure of students to children and, particularly, adults with ID. This concern was described during a focus group discussion with 4th year medical students as follows:

> *"It's very easy when you're sitting in a lecture learning about Down's Syndrome, being taught to look out for probable heart defects, but it would be so much more impressive to actually see those examples in the wards because when you have the patient in front of you it needs to come automatically that you check for one, two, three. It's very different from hearing it in a lecture."* (Focus Group 1, 4th Year Student)

These sentiments were echoed by lecturers in Paediatrics and Neurosciences Departments, who felt that practical exposure was most often opportunistic, based on which patients were available in the wards, and planned exposure was mostly limited to children with ID, rather than adults. Exposure to children was also often limited to those with mild impairments as reflected in this comment*:*

> *"We very seldom see the severely impaired kids. So the medical students in the rotation of Psychiatry in my opinion and in my experience don't really get exposed to it in any real way"* (Lecturer 2, Neurosciences Department).

The second facet does not necessarily suggest that the training is inappropriate, but rather that it is inconsistent as students in their clinical years rotate through different blocks at different hospitals. As such, the exposure and associated teaching differed from one institution to the other. This facet was raised by several Curriculum Implementers across the four Departments:

> *"All the GEMP 3's rotate through Paeds at either Coronation Hospital, Baragwanath or Joburg [Charlotte Maxeke Hospital] so they get different experiences. We try to make it consistent in the tutorial that we give, but I think that the students who go to Coronation Hospital get a bit of a better experience because they get three weeks there and get to sit in and ask questions and interact with the patients"* (Lecturer 2, Human Genetics Department).

With regard to the perceptions on the importance of ID, mention is made in Chapter 3 of this report of the generic nature in which many of the aspects of skills and attitudes were taught to students, rather than teaching them in the context of ID specifically. The primary reason for this was that no case competency existed within the curriculum on the subject of ID. This had an implication for the time allocated to the subject as well as the teaching methodologies implemented:

> *"When you're talking about disability, there isn't a block or specific place where disability is handled. We have an approach to a child with a learning disability, but we don't have an approach to the intellectually impaired"* (Stakeholder, Centre for Health Science Education).

Other disabilities or vulnerable populations were often used as examples in the hope that students will walk away with principles that might be applicable to someone with an intellectual disability:

> *"We had a lecture on deaf patients, so maybe if we had a lecture on mental disability then that would help. It would be more focused."* (Focus Group 1, 4th Year Student).

The generic/integrated approach had resulted in lecturers sourcing or being guided to reference material which was of a similar integrated nature and thus does not support a dedicated approach:

> *"At the moment we don't guide them towards reading materials on intellectual disability. The textbook that we recommend when they get into GEMP 3 and 4 is possibly too integrated for them, because they want to learn things still in chunks"* (Lecturer 2, Neurosciences Department).

Curriculum Implementers justified the lack of focus on the subject of ID as being due to competing subject matters.

> *"At Wits especially, there's a big focus on physical disease and that the kind of softer forms of paediatrics are not given quite the same weight"* (Lecturer 2, Paediatrics Department).

Neurodevelopmental Paediatrics or ID thus falls under this category of 'soft medicine', despite it being a life-long condition with life-threatening complications. In the same vein, it was suggested that the subject of ID cannot be taught effectively when competing against the importance of an epidemic such as HIV/ AIDS:

> *"AIDS has meant that the relevance of children with birth defects in the country has slipped back"* (Lecturer 1, Human Genetics Department).

A similar argument suggested that ID will always be secondary to emergency care in a developing country:

> *"I would think that because of our focus on acute medicine, that they would get less attention here than in other first world countries where children with disabilities tend to come to the fore"* (Lecturer 1, Paediatrics Department).

However, one stakeholder contradicted these sentiments by arguing that regardless of HIV and other acute illnesses, intellectual disability had always been a neglected area:

> *"Whether now or before HIV was around, the interest for intellectual disability never existed"* (Stakeholder, Special Olympics Healthy Athletes MedFest Program).

A Lecturer from the Paediatrics Department was thus of the view that the situation, including the training of medical students, is unlikely to change:

> *"The undergraduate training for disability is poor, including the post graduate and registrar. But in a way, it's understandable because people are managing emergencies 24 hours a day. So getting in to that type of care and rehabilitation is a different type of thinking and mindset. The reactive type of thinking that you need in emergency situations is totally different to sitting down and thinking about the holistic care of a disabled person"* (Lecturer 3, Paediatrics Department).

3.4.2 Adequacy of the Curriculum

There was consensus amongst participants that the time allocated to the teaching of students on the subject of ID was insufficient. This view was specifically shared by Curriculum Implementers from the Departments of Paediatrics and Human Genetics:

> *"They [the students] will come to your Neuro Developmental clinic for maybe half an hour and they'll sit and learn everything about intellectual disability. It's a fallacy that you can take somebody who's had a total of three hours neuro developmental training, put them in a clinic where you've got Cerebral Palsy, Autism, every syndrome under the sun and that you can just expect them to absorb and take out what they need to take."* (Lecturer 2, Paediatrics Department).

The restricted time allocated to the subject of ID resulted in students getting a rudimentary knowledge of the subject – able to manage the basics, but unable to manage complicated cases:

> *"Certainly the level of exposure is not enough that they would be able to handle a child with disabilities. They might realize that this is a child with disabilities and needs to be referred to the Developmental Delay Clinic and that is probably okay"* (Lecturer 1, Paediatrics Department).

The Department of Human Genetics expected the students to come out with a more in depth knowledge and ability to provide basic patient care than that described by the Paediatrics Department above. This was reflected both in the quotation below but also by the fact that this Department covered the Knowledge aspect to a greater extent than other departments:

> *"Our primary issue is the teaching of undergraduates so we have to teach them appropriately. They have to be able to care for people with a disability. They have to be able to have basic recognition and diagnosis for basic problems. They have to understand the treatment that they can apply at a primary health care level. They have to be able to understand what they can't do there, they can refer appropriately to Physio, Occupational Therapy, etc. They also have to be able to give basic counselling and the breaking of bad news and understand the role of psychosocial support. So that's at undergraduate level"* (Lecturer 1, Human Genetics Department).

Contrary to this, one interviewee felt that the students were not coming out of the training with this basic level of knowledge and implied that the teaching was not appropriate since it was not reaching the intended outcome:

> *"I once had a medical officer as an intern who has been through Wits, who has been through the teaching, they need a lot of re-teaching. As far as I'm concerned, what we've taught them is trying to identify that there is a problem but after that, they don't know what to do with the problem"* (Lecturer 3, Paediatrics Department).

This sentiment was supported by a final year medical student who felt incapable of treating a patient with ID unsupervised:

> *"I really wouldn't know how to do a full counselling session with a mother or a family. They might need somebody with a bit more skill. I can do the basics, of course, but I wouldn't feel comfortable treating a patient with ID all by myself"* (Focus Group 2, Final Year Student)

CHAPTER 4: DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

4.1 Introduction

This chapter discusses the main findings from the various components of the study by firstly providing a synopsis of the key cross-cutting findings with regard to the training offered to medical students in relation to treating individuals with intellectual disability. This is followed by a discussion on the strengths and limitations of the study and finally the implications of the results and recommendations.

4.2 Summary of Results

This study used Lennox and Diggens 15 aspects of "ideal curriculum" to investigate the perceptions on the appropriateness and adequacy of training offered to undergraduate medical students to prepare them in managing patients with intellectual disabilities. The findings suggest that Wits University meets at least 12 out of the 15 aspects, but falls short within one knowledge and two attitudinal aspects. In addition the adequacy and appropriateness of the training still render students feeling ill-prepared to manage patients with ID. This finding is mirrored by the results from other studies in which up to 50% of GP's in a UK study were found lacking in confidence caring for adults with learning disabilities subsequent to their training (Messent, 2002). Similar findings have been reported in studies both in Australia, the USA and other parts of the UK by Burge (2002), Lennox, Diggens & Ugoni (1997) and Bradley (1998). The lack of training, skills and sense of being insufficiently prepared has been found to contribute directly to patients with ID remaining without a diagnosis and many being inadequately managed (Beange et al, 1995). Consequently, Shakespeare et al commented that patients with ID receive a poorer service from healthcare professionals and thus have higher rates of morbidity and mortality indicating the gravity of insufficient medical training (Shakespeare et al, 2009).

It is apparent that of the four Departments that participated in the study, the Department of Human Genetics covered the 15 aspects of ID as identified by Lennox and Diggens most thoroughly with 9 of the 15 aspects covered comprehensively and 4 being partially covered. The Family Medicine and Neurosciences Departments on the other hand, covered the aspects the least, with only four aspects being covered comprehensively. A possible reason for this is that there are many genetic causes of ID and many genetic conditions associated with ID which lends the subject best to the Human Genetics Department. Conversely, ID is a very small component of Neurosciences which is made up of both Neurology and Psychiatry and an even smaller aspect of Family Medicine which focuses on personal and professional development as well as public health segments.

Across all of the aspects, the Attitudes Aspects were the least thoroughly covered by all the departments and this was compounded by a sense that these aspects were both difficult to teach and examine (Parker et al, 2012). The lack of teaching on attitudes however does not necessarily determine that students will emerge with an ignorant or intolerant attitude towards the needs of individuals with ID since there is limited research to suggest that the students begin their studies with a negative attitude towards those with ID initially. In addition, the teaching of knowledge and skills alone has been found to positively influence students attitudes (Brown et al, 2002) and that the teaching of positive attitudes is not a strong predictor of positive behaviour (Brown et al, 2002). Despite this justification, there is scope for improving this aspect of the Wits curriculum as the involvement of individuals with ID in leading the teaching on this subject has been found to be the most effective methodology, but is not a methodology that is currently used at Wits. In Tracy and Lacono's study, 4th year students received a lecture followed by direct tutoring from individuals with ID and this method was found to significantly change the students' attitudes, improve understanding and confidence and also result in the students valuing individuals with ID (Tracy & Lacano, 2008).

In addition, of the five aspects of Knowledge, the aspect which was the least well represented was that of 'principles and philosophies of health care for persons with ID.' The lack of teaching on this aspect might suggest that the health needs of this marginalized population are not interpreted as greater than that of the general population and thus issues on equity and accessibility of care are not emphasized. Within the Skills Aspects, all four were found to be thoroughly covered by at least two departments and the skill that was most emphasized was that of training students on counselling and the technique of breaking bad news. This is particularly important since some studies have found that the medical professional training can erode empathy and lead to cynicism and that counseling the patient directly is often a neglected priority (Shakespeare et al, 2009).

The results further revealed that the appropriateness and adequacy of the curriculum was affected by various aspects including teaching and examination methods, allocation of time to the subject, the perceived importance of teaching on the subject of ID relative to other diseases, content of the material taught and the effect of clinical/ practical exposure that the students experience. Inconsistencies were also highlighted between clinical rotations and the practical exposure to patients with ID was limited and mostly opportunistic. This lack of uniformity and lack of dedicated and planned clinical teaching on the subject of ID in the clinical environment resulted in students having different levels of competencies, and undoubtedly affected the confidence of students to manage patients during their internship. The impact of contact time with patients with ID cannot be underestimated and is referenced in numerous studies as being an invaluable tool in fostering understanding, changing perceptions and building confidence in the students (Piachaud, 2002; Shakespeare et al, 2009; Tracy & Lacono, 2008)

Of interest to note is that the curriculum implementers felt that the current training is inadequate and/or inappropriate, attributed this to a severe lack of contact time to teach the students the subject and that this was complicated by the subject of ID not being considered as a priority and competing

against epidemic diseases such as HIV/ AIDS and emergency medicine. Although the latter aspect did not arise in the literature, the lack of teaching time was noted in an Australian study and it was also attributed to being perceived as a small area that is easily omitted (Lennox and Diggens, 1999). Aspects such as time allocation towards a particular subject, presence of examinations on the subject, the attitudes of teachers towards the subject and the teachers' perceived importance of the subject are termed the 'hidden curriculum' (Brown et al, 2002). These are considered to be one of the greatest influencers of students attitudes towards the importance and relevance of the subject and influence their learning of the subject (Brown et al, 2002). Given the comments from the curriculum prescribers above as well as the inadequate time allocated to the teaching of ID, one might assume that these factors are covertly resulting in students perceiving ID as a subject of low priority and low importance which in turn hinders their learning and competency in the subject.

The adequacy of the training was questioned, not overall, but within the South African context. The recurring sense that undergraduate students should only acquire a basic knowledge of ID suggests that there are avenues where qualified Doctors might obtain postgraduate training in this field. However there is currently no ID sub-specialty and only limited postgraduate training available in neuro-developmental paediatrics in South Africa. As a result, those graduating now with a basic knowledge of ID are as qualified on the subject of ID as they are ever likely to become, unless they choose to specialise outside of South Africa. This is not the case in other areas such as the UK where graduates may specialize in ID within the field of Psychiatry and thus levels of required undergraduate knowledge may vary (Burge, 2002).

4.3 Strengths and Limitations

The Lennox and Diggens model used in this study was developed by a panel of eight experts and has been acknowledged as more specific to ID than the former model developed by Khatan et al in 1994 (Piachaud, 2002) which is structured towards disability and rehabilitation teaching. Although the

model provided a particularly useful framework for the study as it is concise, clearly structured and has been used successfully as an assessment tool in Australian Universities previously (Lennox & Diggens, 1999), it was also open to a lot of interpretation. Some aspects of the model such as the reference to community resources and principles and philosophies of health care for ID patients were not explicit and thus required the researcher to develop a definition in order to avoid misinterpretation. There also appeared to be a degree of overlap within the model, specifically between Knowledge Aspect 4 and Skills Aspect 3 and again these areas had to be defined by the researcher before proceeding with the interviews and analyses. A similar criticism might be attributed to the Attitude Aspect which is very subjective for the lecturer, student and even researcher to interpret and even more difficult to judge as having been taught successfully. The fact that the teaching of attitudes scored the lowest is not irrelevant when one considers this limitation, since the shortcomings of the measurement tool, scale and interpretation by all parties may have influenced this finding.

An additional limitation to the model is that it only represents the view point of medical experts and academics, rather than the wider population, health care workers and families of individuals with ID. Given the extent to which studies commend the involvement of allied health professionals in to the teaching process, it might prove beneficial to include them within the development of the curriculum too (Piachaud, 2002).

The comparison between the curriculum at Wits against the Lennox and Diggens model has limitations in that it is dependent on the key informants' interpretation of the extent to which the teaching fulfills the 15 described aspects. The same is true for the interpretation of 'appropriateness' by key informants, focus group participants and the researcher, as it relates to describing the Wits curriculum. However the fact that the study engaged a wide range of respondents including lecturers, students and stakeholders broadened the scope and allowed the interpretations to reflect all aspects of the curriculum. In doing so, it inadvertently also served to verify the information received in the

interviews as often the information received from the students corroborated what the Curriculum Implementer had reported and vice versa. Also, by involving students from both 4th and final years, it minimized the likelihood that the students' responses would be too narrow as they were not expected to recall teaching that they had received 4 or more years prior. This strengthened the study and allowed the students to recall appropriate examples of their teaching.

Although all of the planned focus group discussion took place, the study may have been strengthened by conducting a greater size and number of the groups especially as the experiences of the students at the different hospitals was so varied.

4.4 Conclusions and Recommendations

In conclusion it is apparent that, although the Wits curriculum provides students with a general understanding of the subject of ID and meets 12 of the 15 aspects of the Lennox and Diggens model across the 4 Departments, it fails to produce medical graduates who are thoroughly and equally trained to manage anything beyond simple cases of ID. There is thus scope for improving the quality and consistency of the teaching and the following three recommendations outline steps that might result in this improvement.

1. *Include a case competency (a specific teaching area with learning outcomes) on ID within the syllabus, which will allow at least one department to dedicate sufficient time and attention to the subject.*

2. *Planned practical clinical exposure to patients with ID should be mandatory in the syllabus. One common setting, such as a facility for adults with ID, could be used, through which all undergraduate students could rotate to ensure consistency and where the teaching environment might be controlled to include teaching on all areas where shortfalls currently exist.*

3. *Future research should look at how other South African universities teach the subject of ID, in order to gain a summary of best practices to influence and recommend specific changes to the Wits curriculum.*

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Appendices

Annexure A: Lennox and Diggens checklist of aspects of "ideal curriculum"

1. Knowledge

1.1 Knowledge about the nature, frequency and causes of intellectual disabilities.

1.2 Common health and behavioural problems in people with an intellectual disability

1.3 The impact of an intellectual disability on the individual and his/her family

1.4 Community resources, services and useful medical and non-medical referrals

1.5 Principles and philosophies of health care for people with an intellectual disability

2. Skills

2.1 Skills relating to communication with people who are intellectually disabled and their families

2.2 Examination, assessment and diagnosis of people who have an intellectual disability

2.3 Appropriate referral to and ability to access and liaise with community organisations and specialists

2.4 Resourcing information from carers and other sources.

3. Attitudes

3.1. To treat people with an intellectual disability as an equal

3.2 To look beyond the disability and see the person first

3.3. To have respect and appreciation of the rights of people with an intellectual disability

3.4 To be open to examining one's own attitudes

3.5 Respect for carers information and opinions

3.6 Respect for the wishes and beliefs of people with an intellectual disability and their families.

Annexure B: Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Annemarie van Wieringen

CLEARANCE CERTIFICATE	**M10353**
PROJECT	An Analysis of the Training Offered to Medical Students regarding the Assessment and Treament of Individuals with an Intellectual Disability
INVESTIGATORS	Ms Annemarie van Wieringen.
DEPARTMENT	School of Public Health
DATE CONSIDERED	26/03/2010
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 04/05/2010 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Ms P Ditlopo

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...