OUTCOMES OF IN-PATIENT ADMISSIONS OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES TO A SPECIALIZED UNIT IN CAPE TOWN.

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of MSc Child Health – Neurodevelopmental option.

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DECLARATION

I, **Annette Elizabeth Theron**, declare that this Research Report is my own, unaided work. It is being submitted for the **Degree of MSc Child Health – Neurodevelopmental Option**, at the **University of the Witwatersrand, Johannesburg**. It has not been submitted before for any degree or examination at any other University.

(Signature of candidate)

10th of July 2017, in Cape Town

Dedicated to the staff at the Lentegeur Psychiatric Hospital IDS who work under difficult conditions to help these children and their families with relentless kindness, dedication, compassion, and patience.

ABSTRACT

Children with intellectual and developmental disabilities are often hospitalized for management of challenging behaviour. A recent international trend is the development of specialized units for the containment, assessment and management of such challenging behaviours. A retrospective folder review was undertaken for children admitted to one such unit in Cape Town, South Africa, and the outcomes of these admissions were investigated. The results show that the majority of children admitted to this unit had poor socio-economic circumstances and limited access to community resources. They were admitted for either assessment or respite care. Of those admitted for assessment, improvements were recorded within all behavioural topographies, with the most improvement in destructive behaviours and the least improvement in stereotypy. Improvements were also recorded for basic skills. Neither the presence of autism spectrum disorder, nor pharmacologically controlled epilepsy, had an influence on outcomes. This is a first step towards establishing evidence-based treatment models for this population.

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NOMENCLATURE

ADDIRC – Autism & Development Disorders Inpatient Research Collaborative

ASD – Autism Spectrum Disorder

DD – Developmental Disability

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, 5th Edition

ECD – Early Childhood Development

ID – Intellectual Disability

LAMIs – Low- and Middle Income Countries

LGH – Lentegeur Psychiatric Hospital

LSEN – Learners with Special Educational Needs

MDT – Multidisciplinary Team

SIB – Self-injurious behaviour

WHO – World Health Organisation

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1 INTRODUCTION

1.1 Rationalisation for study

Lentegeur Psychiatric Hospital (LGH), located in Cape Town's Eastern Suburbs, runs an admissions unit for children with intellectual disability (ID). Staff working at this facility feel that this unique service plays an important and much-needed role in the lives of both the children and their care givers. The work is complex and needs multidisciplinary input and innovative approaches in the absence of community resources. As the knowledge base for this type of service is limited, the treatment model followed at this unit has evolved over the years out of the experience of the clinicians and therapists involved, by adjusting interventions described for higher functioning children, to the needs of these children who are largely non-verbal or pre-verbal and have very limited basic skills. Outcomes for these interventions have not been systematically documented.

This study aimed to examine the inpatient services offered to children with intellectual and developmental disabilities by this specialized unit, and to determine the intervention or treatment outcomes. It is hoped that the findings may contribute to addressing the gap in local information and thus lay the foundation for developing evidence based models of care for children with ID who present with challenging behaviours.

1.2 Definitions and Terminology

Intellectual disability (ID) is defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) as a disorder resulting in deficits in both intellectual and adaptive functioning, in three domains (conceptual, social and practical), and which started during the developmental period. Furthermore, the DSM-5 adds severity specifiers to the diagnoses, namely mild, moderate, severe or profound, in line with ICD-10 coding. These specifiers are based on deficits of adaptive functioning, rather than IQ, as this gives a fairer indication of the level of support required, and IQ testing at the lower end of the scale has less validity.(1)

Developmental Disability (DD) is an umbrella term which is widely used internationally, to describe severe chronic disabilities that originated at birth or in childhood, is expected to continue across the life span, and causes significant restriction in functioning. It encompasses intellectual, physical and mental disabilities, and a combination of these.(2)

Challenging Behaviour is described by Eric Emerson in a landmark publication in 1995, as

> "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities." (3)

The currently preferred concept of "challenging behaviour" has developed out of the plethora of terms used over the years, including, but not limited to: behaviour that is aberrant, abnormal, problematic, dysfunctional, maladaptive and disturbed. Emerson & Einfeld prefer the use of the term "challenging behaviour" as it is free from implicit assumptions regarding the behaviour. For example, the term maladaptive implies impaired adaptation to circumstances, however, upon careful analysis, the behaviour could be seen as an adaptive response to a challenging situation. (4)

1.3 Aim & Objectives

This study aimed to examine the inpatient services offered to children with intellectual and developmental disabilities by a specialized unit in a low- to middle income country, and to determine the intervention or treatment outcomes, in order to provide a foundation for the development of evidenced based models of care. The specific objectives of the study were as follows:

Objective 1: To describe a population of children with intellectual disability and challenging behaviours who have received inpatient intervention services from a specialized clinical unit.

Objective 2: To determine the changes in challenging behaviours and skills levels of the children after admission to the specialized unit, as judged clinically by the multidisciplinary team.

Objective 3: To identify factors associated with changes in the children's behaviours and skills levels after admission to the specialized unit.

1.4 Literature Review

1.4.1 Epidemiology

Determining the epidemiology of intellectual and developmental disabilities in children is fraught with difficulty. The WHO's review on Developmental Difficulties in Early Childhood (5) cites three main reasons for this, namely the quality of the studies done, the criteria used to define developmental disabilities, and the use of different research methodology. Maulik et al. determined rates of worldwide intellectual disability through a meta-analysis. They found the overall prevalence of intellectual disability in high income countries to be about 1%, and low- to middle income countries about 2%.(6)

Despite the crucial importance of epidemiological information to determine the need for services, there remains a definite lack of studies done to determine the burden of care in low- to middle income countries, of which South Africa is one. The WHO lists 11 studies that have been conducted over the past 35 years, and gives an indication of epidemiological figures of developmental disabilities in children, in low- and middle-income countries. The most recent of these were published in 2004.(5) An epidemiological study done on 6692 rural children in South Africa in 2002, found a minimum observed prevalence of ID of 35.6 per 1000.(7) The deficit in current, local knowledge is emphasized in a report by Adnams, in a South African overview of epidemiological knowledge, policies and services to people with intellectual disabilities in South Africa (8), as well as by Njenga in a similar article discussing information related to the whole of Africa. (9)

According to the WHO, 10-20% of children in high-income countries experience developmental difficulties. From this the WHO concludes that the prevalence of developmental difficulties is high across the world. They assert that countries with high rates of risk factors that negatively influence child development (such as poverty, malnutrition, infectious diseases, low birth weight, perinatal trauma, and iron deficiency), high rates of childhood developmental difficulties can be expected. (5)

This report by the WHO in itself already highlights one of the fundamental problems in this field, by using the terminology "developmental difficulties" abbreviated as DD. Are developmental *difficulties* the same as developmental *disabilities*, are they more inclusive, less inclusive?

With the prevalence of ID being such an elusive entity, it is even more difficult to determine the population prevalence of challenging behaviour among children with ID. Molteno et al. conducted an investigation into behavioural and emotional problems among children with intellectual disability who attended schools for learners with special educational needs (LSEN) or special day care, in Cape Town. They found a dual diagnoses (psychopathology and intellectual disability) prevalence of 31% among these children, with factors predicting challenging behaviour being male gender, increasing severity of ID, the presence of epilepsy, and ambulation (ambulant children were more disruptive).(10) These findings are in line with those described internationally by Emerson. (4) They do not address the problem of challenging behaviour among children with ID that are not schooled.

1.4.2 Challenging Behaviour

The concept of "challenging behaviour" encompasses a range of behaviours observed in people with intellectual disability, including self-injury, aggression, stereotypical movements, destructiveness, eating inedible objects or severe picky eating, non-compliance to care givers, persistent screaming, disturbed sleep patterns, over-activity, and objectionable public behaviour such as masturbating in public, smearing faeces, or regurgitation of food. These categories are known as topographies of behaviour. (4)

In a comprehensive work that draws on more than 50 years of research into the complexities of challenging behaviour in people with ID, Emerson and Einfeld described the different behavioural topographies, risk factors for the development of challenging behaviour, the issues arising as result of these behaviours, and current best practices in management. These are summarized below: (4)

- Seriously challenging behaviours have their onset in childhood and are highly persistent over time, fluctuating in intensity in response to both environmental and internal factors.
- A broad range of behavioural topographies have been described with much variation within categories. Co-occurrence of challenging behaviour across and within categories is common.
- Consequences of challenging behaviour include a range of negative experiences such as abusive care, physical injury and ill health, development of secondary impairments and disabilities, exclusion from community settings, relationships, activities and services, inappropriate treatment involving long term prescription of neuroleptics, use of mechanical restraints, exposure to abusive psychological treatments, and social and material deprivation and systematic neglect.
- Challenging behaviour can be conceptualized as a complex social phenomenon, and this has considerable implications for evaluating the social significance of the outcomes of interventions.
- Risk factors for people with ID to develop challenging behaviour include:
  - Gender: there is some evidence that males are more likely identified with challenging behaviour such as aggression and destruction of property, but may have similar prevalence of self-injury.
  - Age: prevalence of challenging behaviour increases with age during childhood, peaks during adolescence, reaches a plateau that extends into the mid-thirties, and then declines steadily.
  - Behavioural phenotypes of specific genetic syndromes have been described, including self-injurious hand-wringing in Rett syndrome; hyperphagia and aggression in Prader-Willi syndrome; and hyperactivity, attention deficit, stereotypy in Fragile-X syndrome. Other syndromes that are specifically mentioned are velocardiofacial syndrome, Down syndrome and Williams syndrome.
  - Level of intellectual impairment: in general the increasing severity of the impairment correlates positively with increase in prevalence of challenging behaviour.

- Additional impairments are associated with increased prevalence of challenging behaviours such as having hearing or vision impairment, impairment in communication (being non-verbal or having a specific receptive or expressive language deficit), poorer social skills, sleep disturbances, impairment in mobility and co-occurring mental health problems (ASD, mood disorders, psychoses, PTSD, and anxiety). Other biological factors that have an influence on the occurrence of challenging behaviour include pain, side effects of psychotropic medications, epilepsy, and temperament.
- Setting: challenging behaviours are more prevalent in institutionalised settings and among those with paid carers, however, both the severity of intellectual impairment and the severity of the challenging behaviour are associated with an increased risk of admission and readmission to more restrictive settings. It would appear that the severity of the behaviour is rather a risk factor for admission to more restrictive settings.

Interventions for challenging behaviour have a long history and have historically been the task of psychologists; however child psychiatrists have also been involved. The history, principles and practical aspects of functional behaviour analysis have been comprehensively described by Matson.(11)

1.4.3 Quantitative Measures of Behavioural Change: measuring meaningful outcomes

Research into behavioural sciences is difficult due to the subjective nature of symptoms and outcomes. Quantitative research focusses on the accurate measurement and monitoring of the outcomes of interventions, services and supports. Several different clinical tools have been developed in an effort to quantify challenging behaviour. Traditionally, standardised tools that measure change in duration, frequency and intensity of the challenging behaviour are used to achieve this. Examples of such tools are the Aberrant Behaviour Checklist (ABC), the Strengths and Difficulties Questionnaire (SDQ), and the Clinical Global Impressions Scale (CGI) – these are briefly described below. Emerson & Einfeld explain how, although these tools measure relevant outcomes, they are not necessarily sufficient to plan comprehensive treatment programs. The social validity of a quantified outcome should be assessed to work towards more meaningful outcomes. This expands the context of the outcome from a mechanistic measure of change, to the social significance of the intervention, for all stakeholders (including the patient, care givers and service providers).(4)

The Aberrant Behaviour Checklist was developed decades ago (12), and is widely used in research to measure efficacy of psycho-pharmacotherapy(13) It has recently been used to measure behavioural interventions in autism(14,15).

The Strengths and Difficulties Questionnaire (SDQ)(16) is another scale used to assess the mental health needs of children with ID, and has been validated by Emerson(17). The SDQ can be freely downloaded from the internet and is available in many languages, including three South African languages other than English (namely isiXhosa, IsiZulu and Afrikaans).

The Clinical Global Impressions Scale (CGI) was first developed in the mid 1980's to document an experienced clinician's impression of the status of psychiatric illness at any point during the disease presentation. It consist of an impression of illness severity (scaled 1-7 where 1=normal and 7=very severely ill), and an impression of change (scaled 1-7 where 1=very much improved, 4=unchanged, and 7=very much worse). The CGI has been widely used in research for schizophrenia, bipolar mood disorder and depression, and its potential for routine use in clinical practice was explored by Busner and Targum(18). In his research assessing outcomes for psychiatric admissions of children with challenging behaviour, Siegel compresses the CGI subscale values for change in behaviour into two categorical values, namely "improved" and "not improved".(15)

All the standardised tools must be administered directly to either the patient or care givers and cannot be completed from retrospective clinical records. However, one can probably safely assume that when a child's behaviour has resulted in him being suspended from a school for children with special needs, or warrants an admission to a psychiatric hospital, the CGI-severity score (as an example) would inadvertently be either 6 ("severely ill") or 7 ("among the most severely ill patients").

In the absence of routine administration of standardised tools, the clinical opinion of the multidisciplinary treatment team, formed by expert consensus, must hold some validity in the measurement of treatment outcome. However, it is limited by the lack of standardised test items and inability to quantify the size of change detected.

1.4.4 Hospital Admissions for Children with ID

Children with ID should be cared for at home, especially if they are physically healthy. Yet this is not always possible. Emerson emphasized that institutional provision of services, whether long term or short term, must be seen as system failure, rather than the 'need' of people with intellectual disabilities. (4)

The literature describing inpatient psychiatric treatment for children with intellectual and developmental disabilities (ID/DD), both in general and in specialised units, is limited. This may be due to the focus in recent years on deinstitutionalisation, normalisation, and home-based programmes, yet it is estimated that as many as 10% of children with ID/DD in the United States may require hospital admission for psychiatric treatment yearly.(15,19)

Two distinct types of short term admissions are described in the literature, namely hospitalisations for psychiatric containment, assessment and treatment, and admissions to institutions for respite care. The two different types of admission are both found at the LGH unit.

Psychiatric Admissions for Children with ID

Slevin et al. explain how specialized short term inpatient assessment and treatment is required for the management of people with ID/DD who present with challenging behaviour or mental health problems. It is furthermore explained how these two potential reasons for admission may be complicated as they can co-exist – where challenging behaviour may be the expression of a mental illness.(20)

There is some evidence that inpatient treatment for these children is effective in reducing the intensity of the behaviour as well as the burden of care.(15,21,22)

Four advantages of a short term inpatient interventions are highlighted by McNellis and Harris. Firstly it provides access to a specialized multidisciplinary team, secondly it is part of a treatment continuum that can be stepped up or down at any time, thirdly it provides a safe space for parent training and family interventions, and lastly it provides a space for training of health care workers from the community.(19)

Over the past decade, specialized inpatient units have developed across the world to deal with the very complex nature of the mental health care needs of children with ID/DD.(20,23)

The establishment of the Autism & Development Disorders Inpatient Research Collaborative (ADDIRC) in 2011, headed by M. Siegel, is systematically filling the gap in knowledge based on research done at specialized units in the USA.(24) Siegel et al. gave a short overview of units in the USA providing specialized inpatient care to children and adolescents with ID and ASD, identifying 9 units with fairly similar characteristics, in terms of patient population, length of stay, approach to developing individualised treatment plans, involvement of the multidisciplinary team, and placement options upon discharge. It is also noted that these units serve as valuable training sites for at least one clinical discipline each.(23)

The ADDIRC recently (December, 2015) published their consensus statements on best practices regarding admission of children to psychiatric hospitals for problems related to ID or ASD.(25)

Respite Care Admissions

Respite care is recognised internationally as part of the bouquet of services communities should provide to persons with intellectual (and other) disabilities. The United Nations Convention on the Rights of Persons with Disabilities(26) Article 28.2.(c) seeks State Parties "To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance, and respite care".

Respite care is often a contentious issue between both the primary care givers and the respite care providers. Mannan, O'Brien, McConkey et al. explored the complexities related to the provision of respite care to persons with intellectual disabilities in Ireland. They recognised that the benefit of the respite admission lies solely with the care givers and family members and not with the person with the disability. Furthermore, the care-givers experience ambivalence as they have strong feelings of guilt in relinquishing care, despite recognising their need for it, and they are concerned about the quality of care that will be rendered in their absence.(27) It has also been established that the level of care-giver distress and the severity of the disability are both predictors for the use of respite care.(27,28)

1.5 Conclusion – a public health perspective on challenging behaviours in children with intellectual disability

Emerson and Einfeld(4) assert that the greatest challenge in the field of challenging behaviour lies in the development of “an evidence-based public health approach to challenging behaviours,” and that this would involve “the implementation of a coordinated set of health and social policies to reduce the incidence and prevalence of challenging behaviour among people with severe intellectual disabilities.”

Traditionally public health services have been divided into three levels of prevention. Primary prevention involves reducing the probability of challenging behaviours developing in the first place, by directly addressing risk factors. Secondary prevention involves intervening in the early stages of the development of challenging behaviours. Tertiary prevention strives to provide meaningful outcomes for people who have established challenging behaviour.

Inpatient care, whether short or longer term, is tertiary intervention and should be seen as either a type of targeted intensive therapy, or a last-resort type of intervention. The first line of management should be a community level team effort, between parents, health care workers and educators. Early intervention is the key.

Early childhood development and intervention is widely recognised in the primary prevention of developmental disabilities.(5) Universal strategies are delivered to whole populations and include primary care developmental screening. Targeted strategies are delivered to at-risk subgroups.

According to Emerson and Einfeld, prevention strategies can be seen as “changing the odds” by reducing the exposure to risk, or “beating the odds” by increasing resilience when exposure to risks cannot be eliminated. It is thought that universal strategies aimed at reducing the risk of exposure to adversity (such as violence, abuse, poverty, and psychosocial deprivation) should reduce the prevalence and intensity of challenging behaviours. A second risk factor that can be addressed through universal strategies is the provision of alternative or augmentative communication support, as challenging behaviours can sometimes be conceptualised as adaptive responses to communication deficits. A third strategy is to provide parenting interventions and family counselling – these may have to be targeted at identified at-risk families or in the early stages of the development of challenging behaviours. Resilience enhancing interventions should start as early as possible and continue throughout the life-course. These are interventions that provide opportunities for people with intellectual disability to have positive life experiences that enhance self-esteem and instil a sense of mastery, self-determination, and achievement.(4)

When considering how early attachment influences social behaviour in later life(29), another universal prevention strategy should be to identify early attachment difficulties and intervene as soon as possible, especially in the group of children already identified as at risk for developmental disability.

Tertiary prevention services for people with ID and challenging behaviour is not widely available, in fact Emerson has written extensively on the matter that the majority of people with challenging behaviour do not receive effective support services, and that most countries do not have effective behavioural support services routinely available through their educational, health and social services.(4)

The development of challenging behaviour should be seen in the broader light of public health in general. The effects of primary attachments, family dynamics and socio-economic circumstances should all be taken into account when planning support services, rather than looking at the individual with the challenging behaviour as a social offender.

2 METHODS

2.1 Study design

A retrospective folder review and analysis of patient records was conducted. The nature of the presentation of these cases was complex, and it was not feasible to try to select a control group before this preliminary study was undertaken.

2.2 Study Location

The study site was the inpatient unit for children with ID/DD at Lentegeur Psychiatric Hospital's Intellectual Disability Service, located in Mitchell's Plain, Cape Town, South Africa. The geographical drainage area for children with intellectual disability who are admitted to the inpatient unit, is all regions of the Western Cape Province.

It is a 15-bed unit however, the bed-occupancy is low, averaging about 40-45%. The maximum the unit can manage is considered to be around 10, given the high care needs of this patient population, otherwise the staff:patient ratio becomes too low. Often extra nursing staff are required for one-on-one nursing to ensure the safety of both the challenging patient and those around them.

The communities served by this unit are largely low-income areas including the poverty stricken and gang-infested areas of the so-called Cape Flats area, including Mitchell's Plain and Khayelitsha, as well as rural areas further afield in the rest of the Western Cape. A small percentage of clients are also referred from the private health care sector, as there is no parallel facility in the private service.

2.3 Treatment Program

LGH IDS currently serves children with ID and their care givers both on an outpatient and inpatient basis.

The outpatient services provide the foundation for children and their families. Children are referred here from the catchment area – at the time of the study, the catchment area consisted of the whole of the Western Cape Province, however this has recently changed and about half the province now refers to the new outpatient service for children with ID established at Alexandra Hospital in Maitland.

Children who are referred to this service have already come through the paediatric services of high risk, neurodevelopmental and/or neurology clinics. For the most part they have been fully worked up in terms of diagnoses, and most have received some form of therapy aimed at early childhood development (ECD), mostly occupational therapy, physiotherapy or speech therapy, or a combination thereof. It is no secret that these services are more accessible within the Cape Town metro area, and already outside of a 50km radius from the city, services are greatly diminished. Community members deliver limited ECD with whatever resources they can muster. Significant work is being done at faraway places such as Elim, George and Worcester. However, it still often happens that a child arrives at the PGC at near school-going age, without proper diagnoses and no history of intervention. This problem is compounded by the influx of foreign nationals in search of better health care services.

Once referred to PGC, a child and his or her family will undergo a multidisciplinary team (MDT) assessment as a first point of contact, from where a therapeutic plan will be developed based on the most pertinent needs. This mostly consists of outpatient appointments for assessments and therapy by the MDT. LGH IDS currently has almost a full complement of MDT members, including a psychiatrist, medical officers, social worker, two senior psychologists with 2-3 interns, occupational therapist, physiotherapist, professional nurse, and a dietician is available on an ad hoc base. The current gap in the service is for a speech therapist, and recently a music therapist has done some great work on a part time basis. These clinicians and therapist liaise with other service providers from the area, including medical specialists from the tertiary hospitals and other health care workers from the community.

When it becomes clear that the outpatient support being provided is insufficient for the complexity of the case, or the urgency of the intervention exceeds the abilities of the outpatient services, ward admission is considered.

Admissions for children with intellectual disability at LGH are for the most part considered as either urgent or elective, with acute cases having to go through the acute district hospital services as provided for by the mental health care act. Cases being admitted electively are mostly fully worked up and assessed by at least initial screening assessments from the members of the MDT, and have been seen and discussed at the out-patients clinic. On rare occasions the child to be admitted comes from an area too far away from Cape Town and pre-admission screening is not feasible. In these cases the team relies heavily on colleagues from the referring area to have done MDT assessments and already have implemented strategies to improve the circumstances.

Admissions generally have three overlapping phases:

- settling in, assessment and observation
- implementation of therapeutic strategies
- graded discharge plan

The average child takes about 2-3 days to settle and get used to the ward surroundings, and a few days more to get used to the strict routine that is maintained and can be expected. During this time the child will be observed and different team members will do in depth assessments starting by the middle of the first week. Within 4 days after admission, the case is presented at the MDT meeting and an initial plan of action is formulated. Simple behaviour modification strategies are implemented from day one and by the second week, it becomes clear what specific strategies may have to be implemented. Therapeutic strategies are mainly implemented from the third week onwards, and once the child has stabilised and shown a change in behaviour, the duration of the admission is determined as well as a graded discharge plan which includes weekend visits home before the final discharge day. Care givers are strongly encouraged to participate as much as possible in ward activities in order to learn how to implement behavioural strategies and routine.

An outflow of therapeutic admissions, are the respite admissions. As part of the comprehensive package of care offered to these children and their families, respite is offered to families for a maximum period of 14 days. These children are then admitted alongside the admissions for therapeutic assessment, and participate in all therapeutic group activities, however they do not undergo further assessment, their care givers are not expected to participate in the program, and very rarely do they get any changes made to their chronic therapy. One reason to not grant a child respite care, is that it could potentially cause the child to miss school, therefore most respite admissions occur over the major holiday periods.

All children admitted, whether for therapeutic or respite period, are examined and clerked by a medical officer who may also act as a case manager. They are also thoroughly evaluated by a professional nurse. All cases are discussed at MDT meetings on a weekly basis. All cases are seen in groups by the occupational therapist and physiotherapist. All therapeutic cases are assessed individually by the occupational therapist and a psychologist. All cases are known to the psychiatrist and the social worker and they evaluate cases as the need arises. The dietician is consulted as needed. Recently a music therapist has done weekly group sessions with selected cases. It is hoped that this will become a permanent fixture.

Currently the inpatient service could be improved by the edition of two MDT members, namely a speech and language therapist, and an educator.

2.4 Study group

The study participants were boys and girls aged 5-13 years, who were admitted to the LGH unit for children with ID over a 24-month period (1 July 2013 to 30 June 2015).

A list of admissions to the unit for children with ID, obtained from the IDS admissions records, revealed 140 admissions during the 24 months between 1 July 2013 and 30 June 2015. Of these admissions, 8 were for children 14 years or older and 2 for children younger than 5, and these were excluded from the study. The remaining 130 admissions were subsequently divided into two groups according to the type of admission, namely respite or assessment, as described above.

Table 2.4.1 Number of Admissions Analysed

Type of Admission	**Initial number of admissions**	**Exclusions**	**Total number of children (n)**
Assessment	77	3 (excluded)	74
Respite	53	39 (repeat admissions)	14
Total	130	42	**88**

From the assessment group, 3 admissions were excluded. These were children who were initially admitted electively for assessment but were subsequently discharged within 7 days due to various reasons, and then admitted for the full assessment period a few weeks later. Reasons for these premature discharges were as follows:

1. The child developed a severe febrile illness a few days after admission and was sent for treatment to the district hospital paediatric services, from where she was discharged

home. She was admitted a few weeks after recovery for a full period of assessment and intervention.

2. The day after admission, the care givers were notified of an appointment for dental extraction under anaesthesia at the tertiary hospital the following week, so she was discharged to be readmitted once recovered.
3. The child's mother was very anxious about leaving him in the care of hospital staff and decided to take him home after 2 days. He was admitted a few months later for a full period, once his mother felt more comfortable with the service.

From the respite group, 14 children had been admitted during the study period for respite only, some of them multiple times. Combined with those that were admitted for a period of respite after an initial assessment, there were a total of 53 admissions for respite.

Taking into account the above-mentioned exclusions and multiple admissions, the clinical records of 88 children were scrutinized.

2.5 Data Collection and Management

Data was collected from the clinical records of each child by the principle investigator over a six week period, using a data sheet and entering the data into an excel spread sheet. The data was de-identified by assigning a number to each admission. Data was kept on a password protected computer.

2.6 Measures

In order to reach the three objectives of the study, three types of information was collected.

Firstly, data regarding the individual was collected, including: age, gender, length of admission, level of ID, aetiology of ID, and comorbid physical and psychiatric diagnoses.

Secondly, data was collected indicating social circumstances and access to community resources, including area code of home address, type of housing arrangement, family/care structure, whether receiving financial aid (care dependency grant), school placement and attendance, and where the referral originated from.

Thirdly, data describing the specific behavioural problems and skills deficits encountered in each child is described. There is currently no routine clinical tool being used at the LGH unit to describe the presentation of behaviour or its change in relation to therapy. However, this does not mean it is not recorded. For each child the presenting behavioural problems are fully explored and recorded through parent interviews and clinical observations. Target behaviours and skills are identified and discussed by the MDT, and specific strategies are implemented. By the time the discharge is planned, the MDT will record their impressions of the changes that have taken place for each behaviour and skill that was targeted during the admission.

Information regarding the following 12 behavioural topographies was collected: aggression, impulsivity, hyperactivity, oppositionality, destruction of objects/property, disregarding danger, self-injurious behaviour, picky eating, sleep disorder, stereotypy, inappropriate sexual behaviour, and encopresis / smearing faeces. For all children, the presence or absence of these behavioural topographies on admission were recorded, and for the 74 children admitted for assessment and intervention, the outcomes were recorded.

As discussed above, it is not possible to retrospectively apply a descriptive tool accurately to assess behavioural profiles, therefore the clinical impression formed by the MDT was used as the outcome measure, and change in behaviour was recorded as clinically “improved”, “unchanged”, or “worsened”. Outcomes were not recorded for children who had been admitted for respite care only, as these did not receive comprehensive interventions. It will be shown that there was great inter-individual variability into the number of different topographies found in each child, as well as in the changes that occurred for each child.

Skills profiles were described in 5 areas as follows:

- Speech – non-verbal, using single words, using phrase speech, or using full sentences.
- Feeding behaviour – no attempt to feed self, feeding with fingers only, or using a utensil (mostly a spoon) to feed.
- Toileting behaviour – no indication of needs, some indication of needs, some continence achieved (will use the toilet when reminded), mostly continent (occasionally has accidents but do not need constant reminding), or independently continent.
- Play – no interest in toys or games, some interest in toys or games but very restricted or fixed in repertoire, or appropriate play for developmental age.
- Interaction – shows no interaction with others individually or in groups (not in initiating nor responding), shows some interaction with others in groups, or shows appropriate

interaction for developmental level. This refers to interaction with both adults and other children.

These 5 fields were described for each child, and as with the behavioural topographies, the outcomes where described for children admitted for assessment, and skills outcomes were also recorded as a clinical impression of “improved”, “unchanged” or “worsened”.

2.7 Ethical Considerations

Ethical clearance was obtained from the University of the Witwatersrand, Johannesburg’s Human Research Ethics Committee, and the Department of Health. (Ethics Certificate attached as Appendix A.) As this was a folder review study, no consent was required from participants. Data was collected from the files anonymously and subjects have been de-identified by coding to protect their privacy. Data sheets are kept in a locked room, and computer files are password protected.

In this report, all effort is made to approach this field of difficulty with compassion and respect to the people involved, both to patients and their care givers and health care workers.

2.8 Data Analysis

Data were entered into Excel spread sheet and analysed using Excel Data Analysis functions, the Real Statistics Resource Pack for Excel(30). Chi square statistics and p-values for 2x2 tables were calculated using the StatPages open source calculator(31), and for 2x3 tables using the Social Science Statistics online Chi-Square Calculator(32).

Demographic data are categorical variables and are expressed as percentages and presented as frequency tables and graphs.

Age and duration of admission is expressed as continuous variables. Their central tendencies are indicated through arithmetic means, and their measures of dispersion through range and standard deviation.

Behavioural profiles are presented as frequency tables. Missing information is adjusted for as follows: from the assessment group, the skills outcomes for 2 children were missing, so the number was reduced to 72 for those calculations; the behavioural profile and skills description of one child admitted for respite was not available and the number was reduced to 13.

Outcomes were recorded as improved, unchanged, or worsened. Only three children showed any worsening of behaviour, although many improved somewhat and then reached a plateau and some regressed after initial improvement so that overall their behaviour was unchanged by discharge. It seemed reasonable to then condense the categories of "worsened" and "unchanged" into one category of "not improved".

Behavioural outcomes are tabulated as proportions of the number of children that presented with the specific behaviour, who improved. Skills outcomes are tabulated as proportions that improved, of the entire assessment group, as each skill attained was described for each child.

Behavioural and skills outcomes (improved vs not improved) are investigated in relation to different independent variables. This achieves a cross-tabulation (either 2x2 or 2x3 depending on the grouping) and differences in outcomes between groups were correlated using chi-square test and Fisher's Exact Test (for behaviours with small sample sizes), with $p<0,05$ taken as statistically significant. The independent variables explored are: level of ID, Gender, Age, comorbidity with ASD, ADHD or epilepsy, attendance at an educational facility, care structure at home, type of housing lived in by the child, and verbal communication ability. The number of children grouped with each variable is indicated with the variable. The results for behavioural outcomes have to be interpreted with caution due to the low numbers in some of the groups. For the skills outcomes, the numbers are stable, as each of the five skill areas were documented for each child, except two for whom it was missing. The missing data were left out of the calculations, keeping the total number of children in the group at 72. For each variable the distribution across the study population is indicated as a number.

2.9 Limitations of the Study

The study is subjected to selection bias through its design as an uncontrolled case series, however large the case series may be. However, the information obtained through an uncontrolled study is not invaluable, as explained by Sacca in an article discussing uncontrolled clinical trials.(33) The results have to be interpreted with caution and cannot be generalised to groups outside of this specific population – it cannot be extrapolated to children who are not admitted to an institution specializing in children with ID, and it cannot be generalised to children outside of the unit’s referral areas, or to adults.

It was anticipated that the amount and accuracy of information captured in clinical records may extensive, however this was not the case, and the small amount of missing data is discussed under data analysis.

The outcomes measure for behavioural and skills interventions are based on expert clinical opinion, often derived from the combined opinion of the MDT, rather than a standardised assessment tool. The binary nature of the outcome (improved vs not improved) implies that there is no measure of the degree of change, only that change has happened or not. There is also no temporal indication to this change, and within the cross-sectional design of the study, there is no indication of the measure of change sustained over time.

The initial power analysis for this study did not take into account this amount of variability in the presenting behavioural profiles, in many cases the sample size could be too small to show the presence of a significant difference when the outcomes are related to independent variables.

3 FINDINGS

3.1 Demographic Description

3.1.1 Gender & Age

Of the 88 children who were admitted over a two-year period, the overwhelming majority was male, and the male to female ratio was 3:1. As discussed above, there were two mutually exclusive indications for admission, assessment and respite. Figure 3.1 shows the gender distributions across the two groups, as well as the total study population.

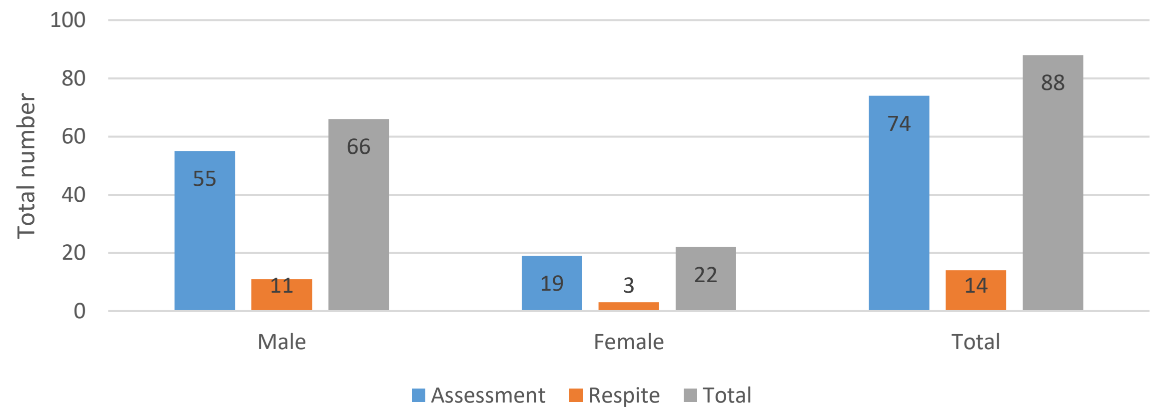
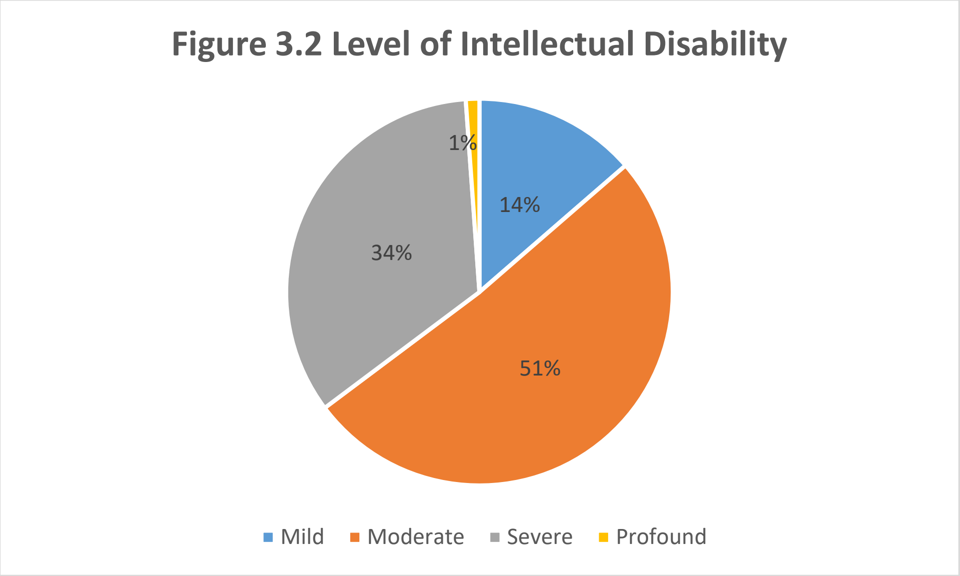


Figure 3.1. Study Population

Table 3.1 Age Distribution of Patients

	Age range (years)	Mean (SD)
Assessment group N=74	5,57 – 13,38	8,62 (2,06)
Respite group N=14	8,28 – 13,68	10,96 (1,67)
All admissions N=88	5,57 – 13,68	9,00 (2,18)

3.1.2 Level of ID



The distribution of the study population across the four levels of ID is shown in figure 3.2, as a percentage of 88 patients.

3.1.3 Aetiology of ID/DD

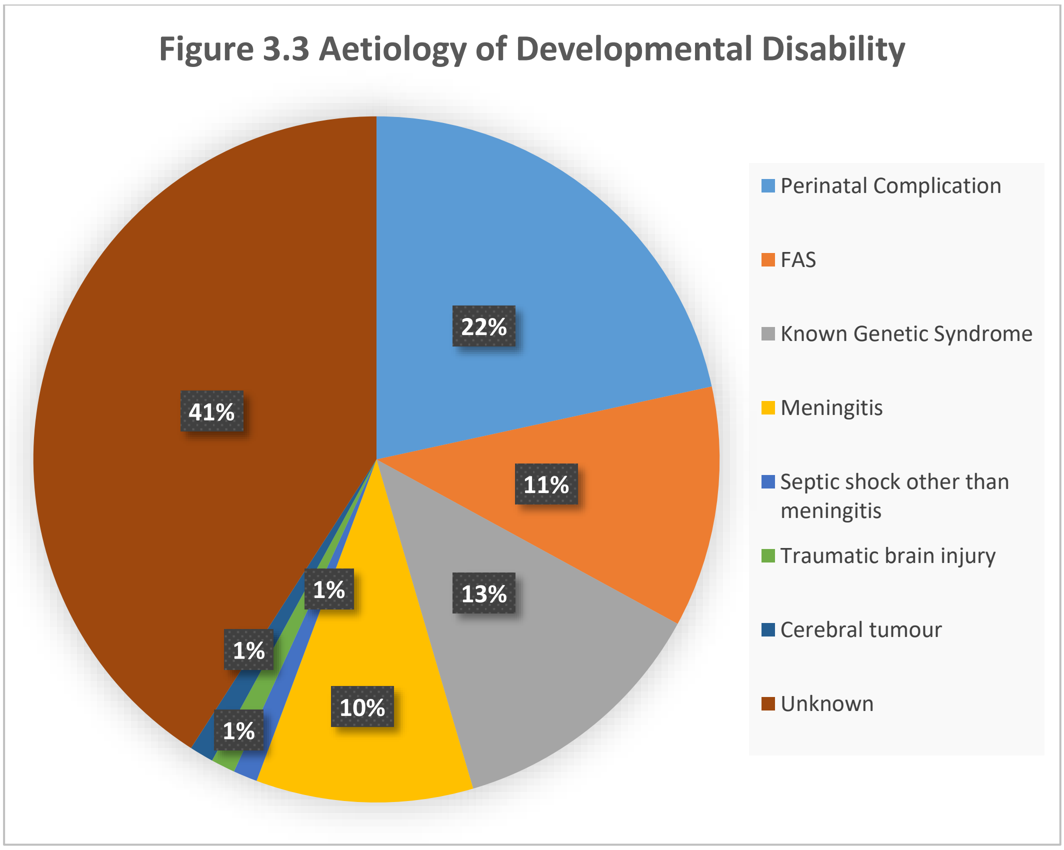


Figure 3.3 gives a simplified version of what was found in this study population.

Table 3.2 below shows the number of children that are captured under one of the categories above and also have a history of one or more other confounding aetiologies. This table is by no means comprehensive, it only captures the confounders that had been recorded in the clinical notes and do not represent a systematic enquiry. It only serves to illustrate the complexity of aetiological determinants.

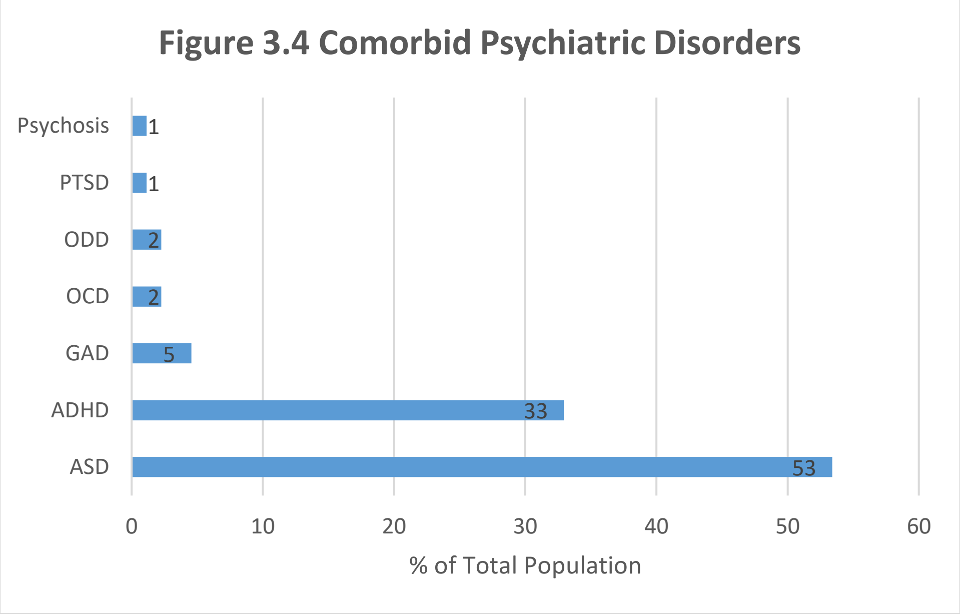
Table 3.2 Multiple Aetiological Confounders

	Number of Children
Premature Birth	9
Gestational Hypertension	7
Dysmorphic features present but genetic diagnoses not made	5
HIV exposed but not infected (successful PMTCT)	2
Illicit drug abuse in pregnancy	2
Suspected non-accidental head injury	2
Lithium used in pregnancy	1
Attempted home abortion	1
Twin pregnancy	3

3.1.4 Comorbid Conditions

Psychiatric Disorders

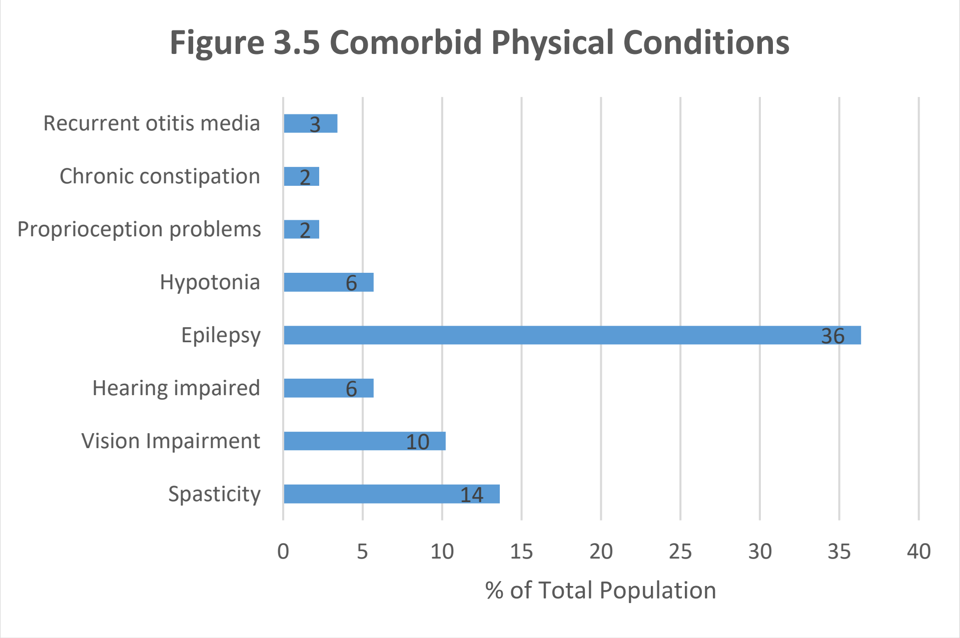
Figure 3.4 shows the comorbid psychiatric diagnoses found in the study population. These were pre-admission diagnoses. Not all the children had psychiatric diagnoses comorbid to their ID, but a child can have more than one psychiatric diagnosis, therefore percentages do not add up to 100.



Legend: PTSD – post traumatic stress disorder; ODD – oppositional defiant disorder; OCD – obsessive-compulsive disorder; GAD – generalized anxiety disorder; ADHD – attention deficit hyperactivity disorder; ASD – autism spectrum disorder.

Comorbid Physical Conditions

As with the psychiatric comorbid conditions above, a child can have more than one physical condition, and some children have no physical problems and are physically robust and healthy.



3.1.5 Environmental Factors

An effort is made here to illustrate the difficult social circumstances of most of the children.

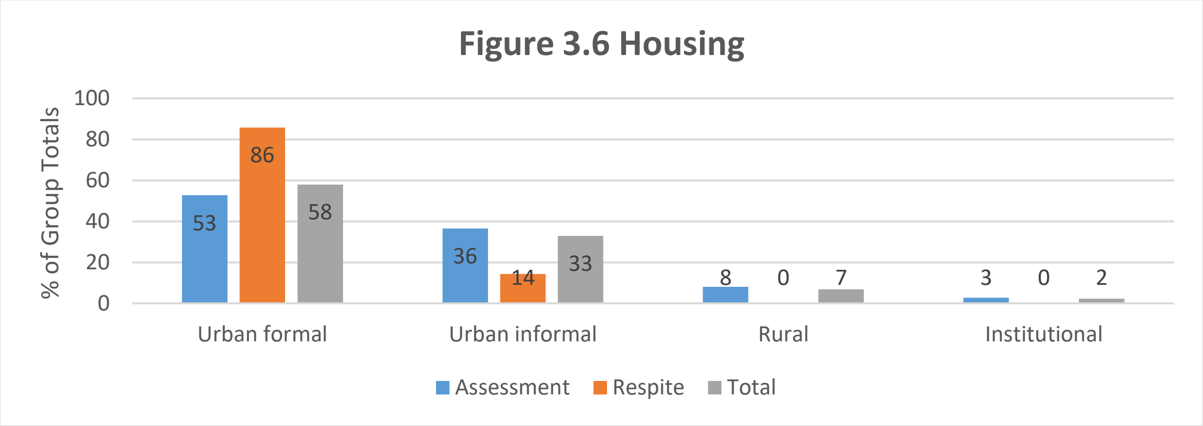
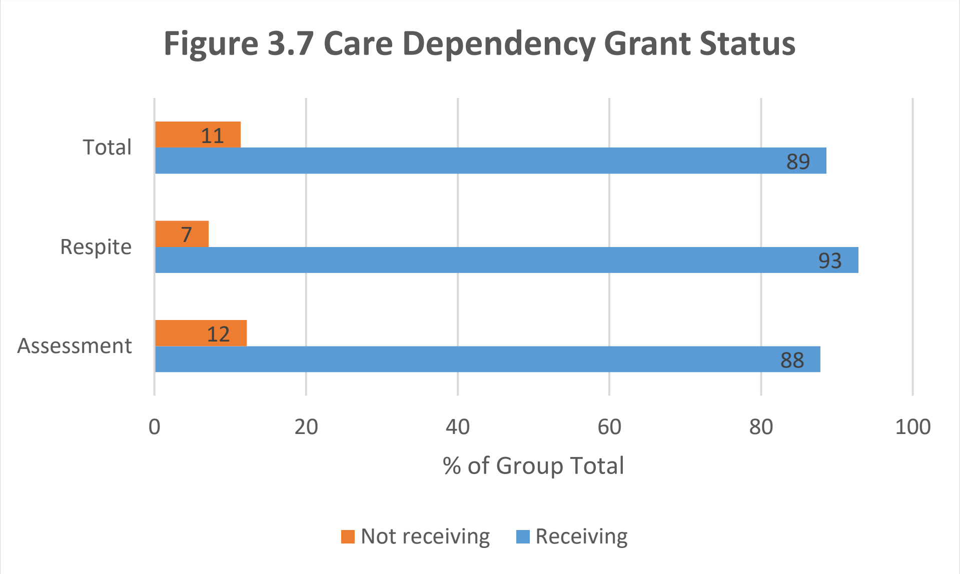
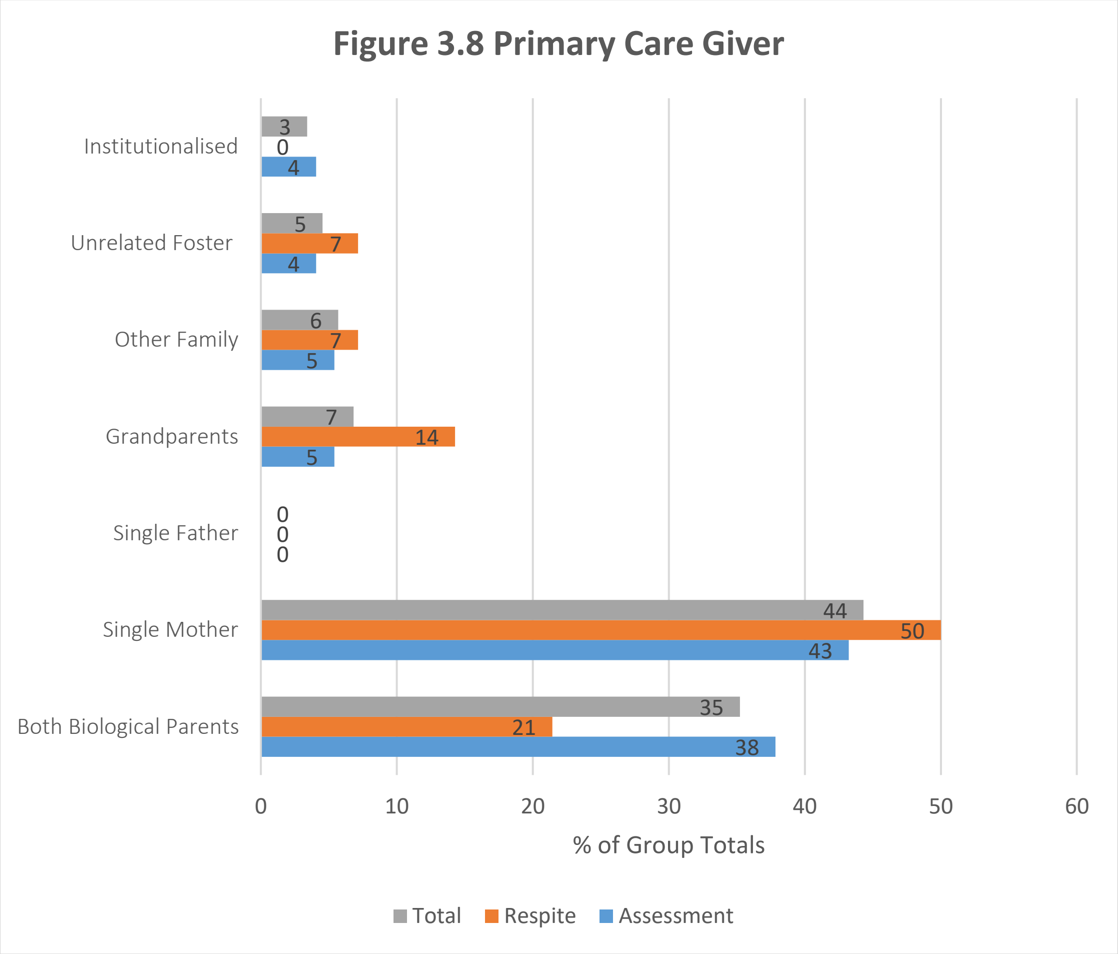


Figure 3.6 shows crude categories of housing. Two children were institutionalised, and 6 were referred from farms in the Western Cape where they lived with their parents in farm labourer's accommodations or in rural accommodation. The rest lived in the greater Cape Town area. Urban formal housing is defined as a house built with conventional building materials and that has an inside flushing toilet and electricity. Urban informal is defined as a make-shift building (materials often used include corrugated iron and wood), and toilets are communal outside of the house, they may or may not have electricity – this includes people living in a "Wendy" house on someone's yard who have to access the toilet facilities in the main house.

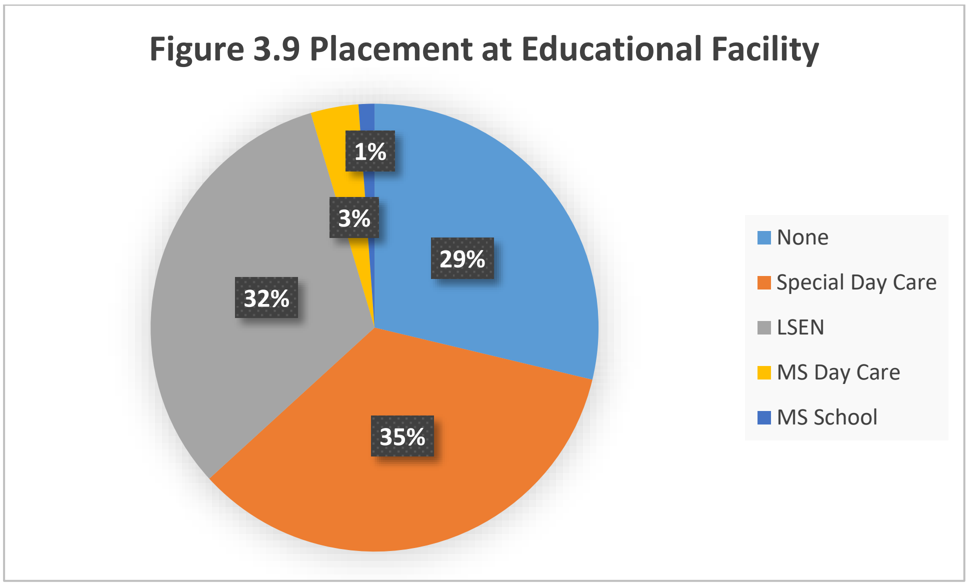


Care dependency grant status for these families is indicated in figure 3.7. This is the financial aid granted by social services to families of a child with high care needs. These grants are awarded to families who can prove that their monthly income is so low that they are unable to adequately provide for the child's care needs. This money is often used for transporting the child to and from medical services or special schooling. The reality is that often this child becomes the "bread winner" in a poverty stricken family, where the care dependency grant is the only regular source of income for a whole family. This figure does not take into account families where there are other grants awarded for other reasons, including pension, foster care, or adult disability grants.

Figure 3.8 shows all too clearly how often children with ID and challenging behaviour live within fractured families. Even the families that have both biological parents at home, do not give any indication of the presence of marital conflict.



3.1.6 Community Resources Accessed



Legend: MS = main stream, LSEN = Learners with Special Educational Needs

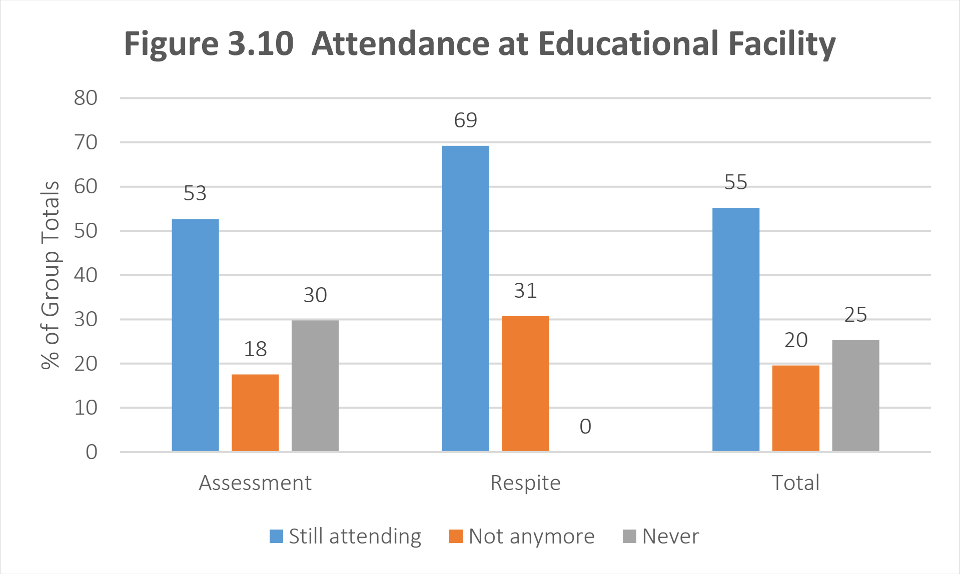


Figure 3.11 gives a breakdown of attendance at a schooling facility.

Figure 3.11 Details of Educational Facility Attendance

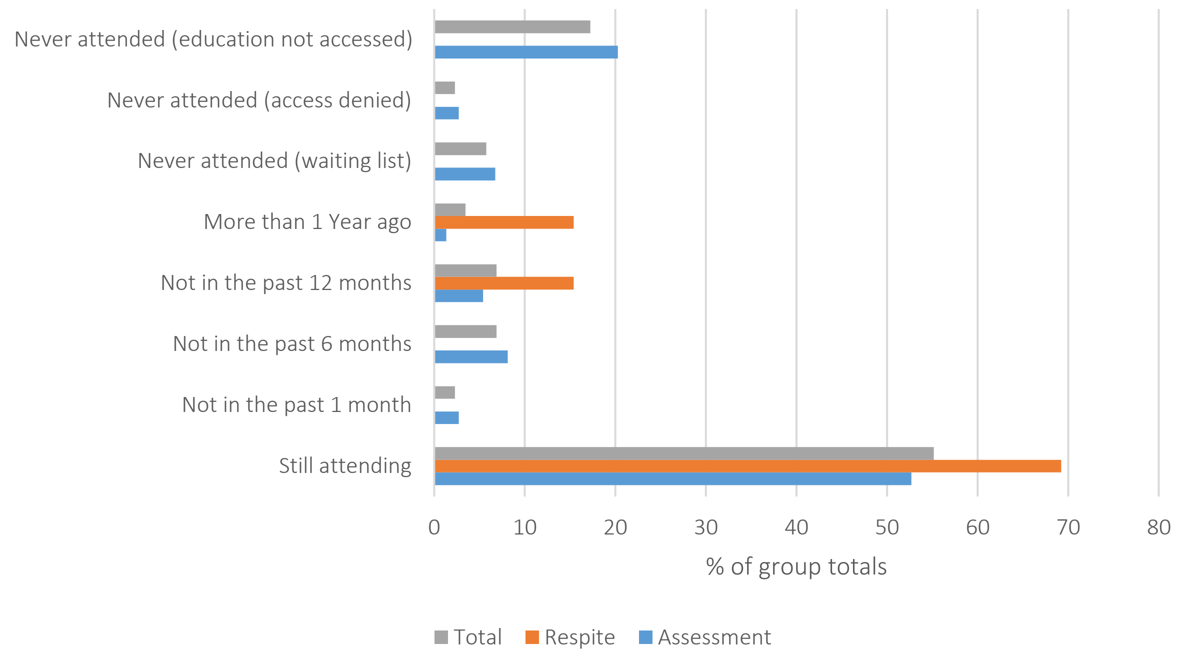


Figure 3.12 Reasons for Not Attending Educational Facility Anymore

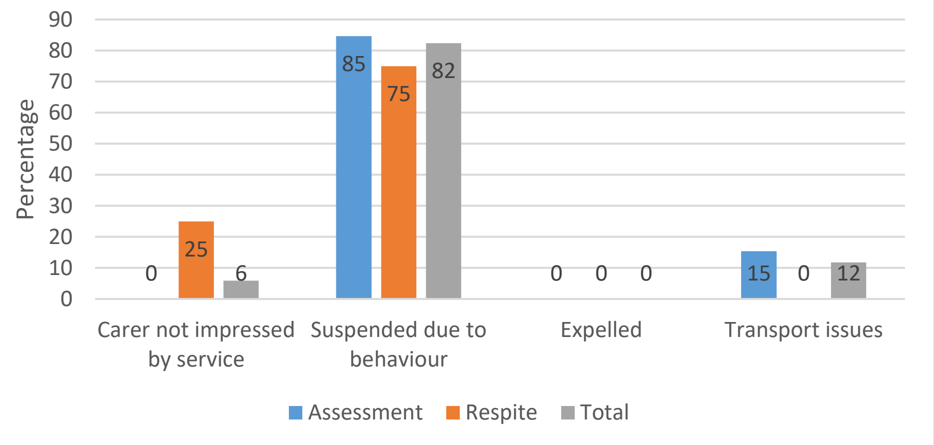
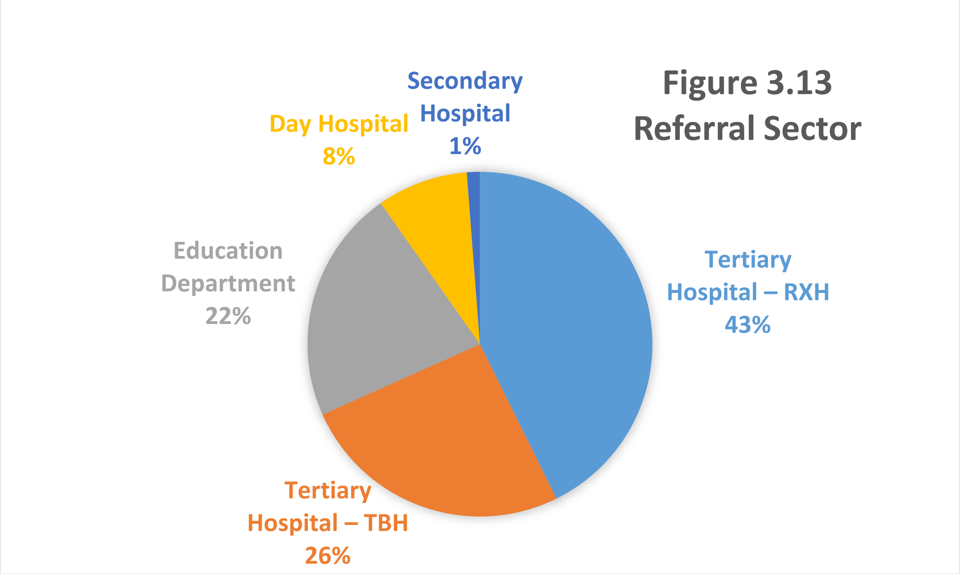
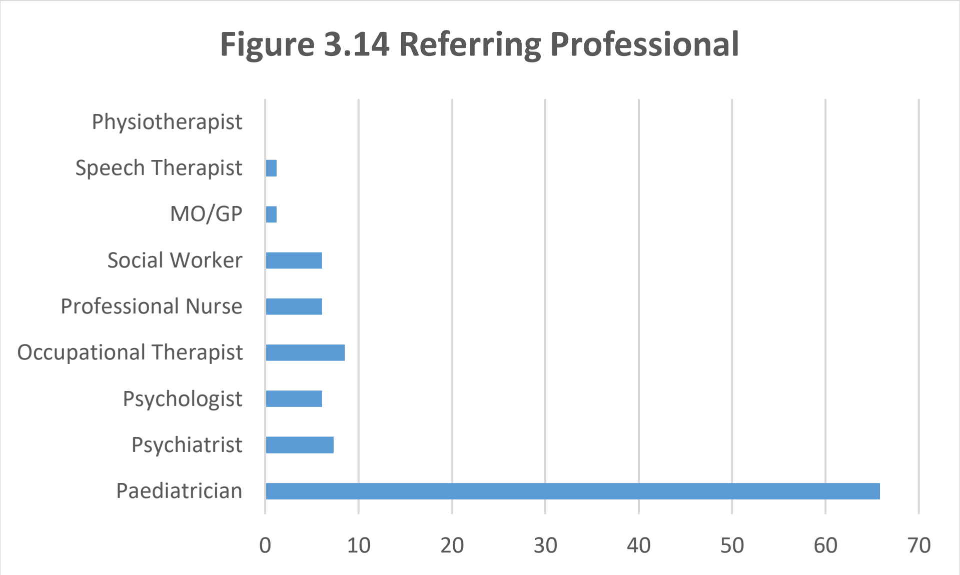


Figure 3.12 illustrates the reasons for the 20% of the study population not attending an educational facility anymore.



Figures 3.13 and 3.14 show the point of entry to the LGH IDS, and the referring professional.



3.2 Types of Admissions: Assessment and Respite Care

3.2.1 Assessment Admissions

The duration of stay for the children in the assessment group is summarized in table 3.3. Figure 3.15 shows the admission duration spread for this group.

Table 3.3 Assessment Admissions: Duration of Stay

	Min	Max	Mean (SD)	Median
Duration (days)	2	161	46 (27)	44

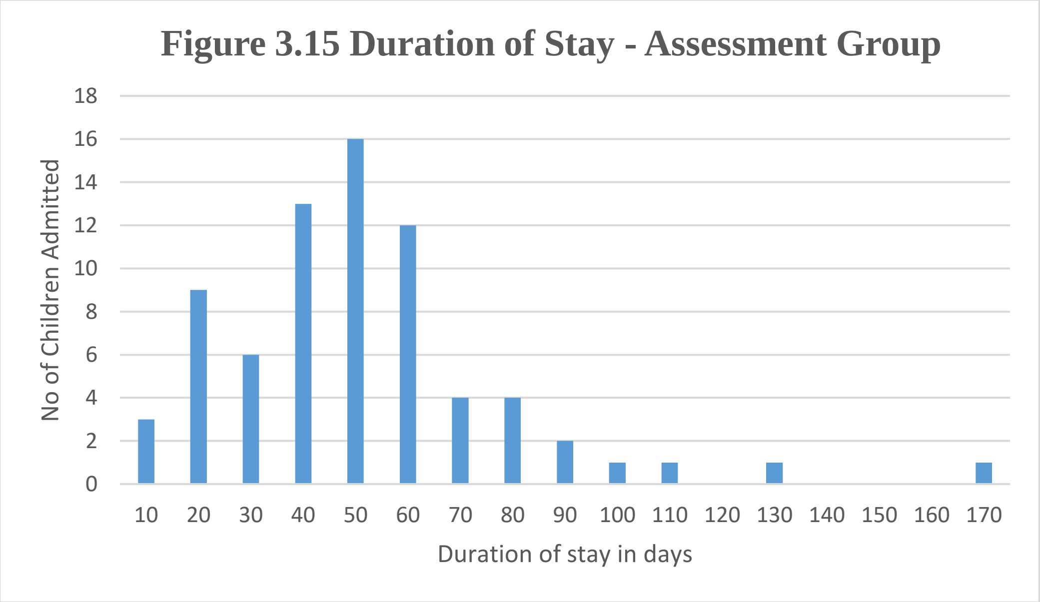


Figure 3.16 shows the behavioural profiles of the children admitted for assessment. Each behaviour is shown individually as a percentage of the children in which it occurred.

The skills description is shown in Table 3.4. This illustrates the basic self-care skills levels in terms of activities of daily living.

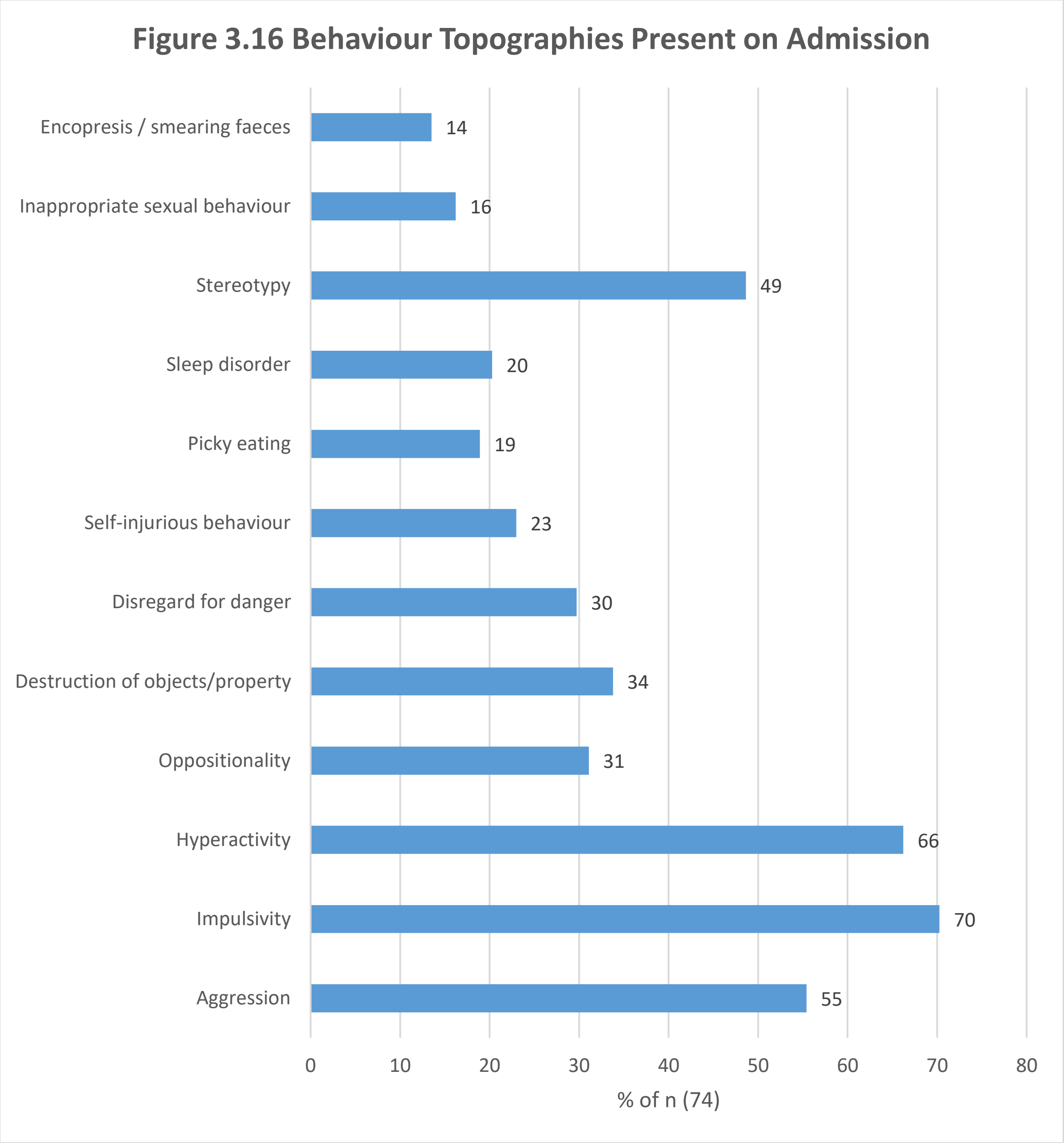


Table 3.4 Description of skills on admission for assessment

Skill	**Profile**	**N = 74**	**% of N**
Speech	None	29	39
	Single words	29	39
	Phrase speech	12	16
	Full sentences	4	5
Feeding	No attempt	5	7
	Fingers	22	30
	Utensil	47	64

Toileting	No indication of needs	19	26
	Some indication	21	28
	Some continence	8	11
	Mostly continent	14	19
	Independently continent	12	16
Play	No interests	17	23
	Fixed interests	37	50
	Appropriate*	20	27
Interaction in groups	None	23	31
	Some	32	43
	Appropriate*	19	26

*Appropriate for developmental age.

Psycho-pharmacotherapy

Table 3.5 below summarizes psycho-pharmacotherapy as practiced at the unit during the study period. It shows how very few agents were added after admission. All therapeutic agents' indications and dosages were revisited during the assessment with subsequent changes in dosages and termination of some agents. The five most frequently prescribed agents are indicated in bold.

Table 3.5 Psycho-pharmacotherapy practised during the assessment admissions

Agent	Present on admission				Added after admission			
	unch	incr	decr	term	unch	incr	decr	term
Risperidone	**16**	**2**	**10**	**2**	**1**	0	0	0
Methylphenidate	**7**	**4**	**2**	0	**2**	**8**	0	**3**
Fluoxetine	**1**	0	0	0	0	0	0	**1**
Citalopram	0	0	0	**1**	0	0	0	0
Clonazepam	0	0	0	**1**	0	0	0	0
Sodium Valproate	**15**	**1**	0	**1**	0	**2**	0	0
Carbamazepine	**5**	0	0	0	**1**	0	0	0
Clobazam	**2**	0	0	0	0	0	0	0
Lamotrigine	**5**	0	0	0	0	0	0	0

Imipramine	**3**	0	0	**1**	0	0	0	0
Trimeprazine	**6**	0	0	**1**	**1**	0	0	0
Lorazepam	0	0	0	**1**	0	0	0	**1**
Clonidine	0	0	0	**1**	0	0	0	0
Chlorpromazine	**1**	0	0	0	0	0	0	0
Melatonin	**1**	0	0	0	0	0	0	0

Legend: unch – unchanged; incr – increased; decr – decreased; term – terminated.

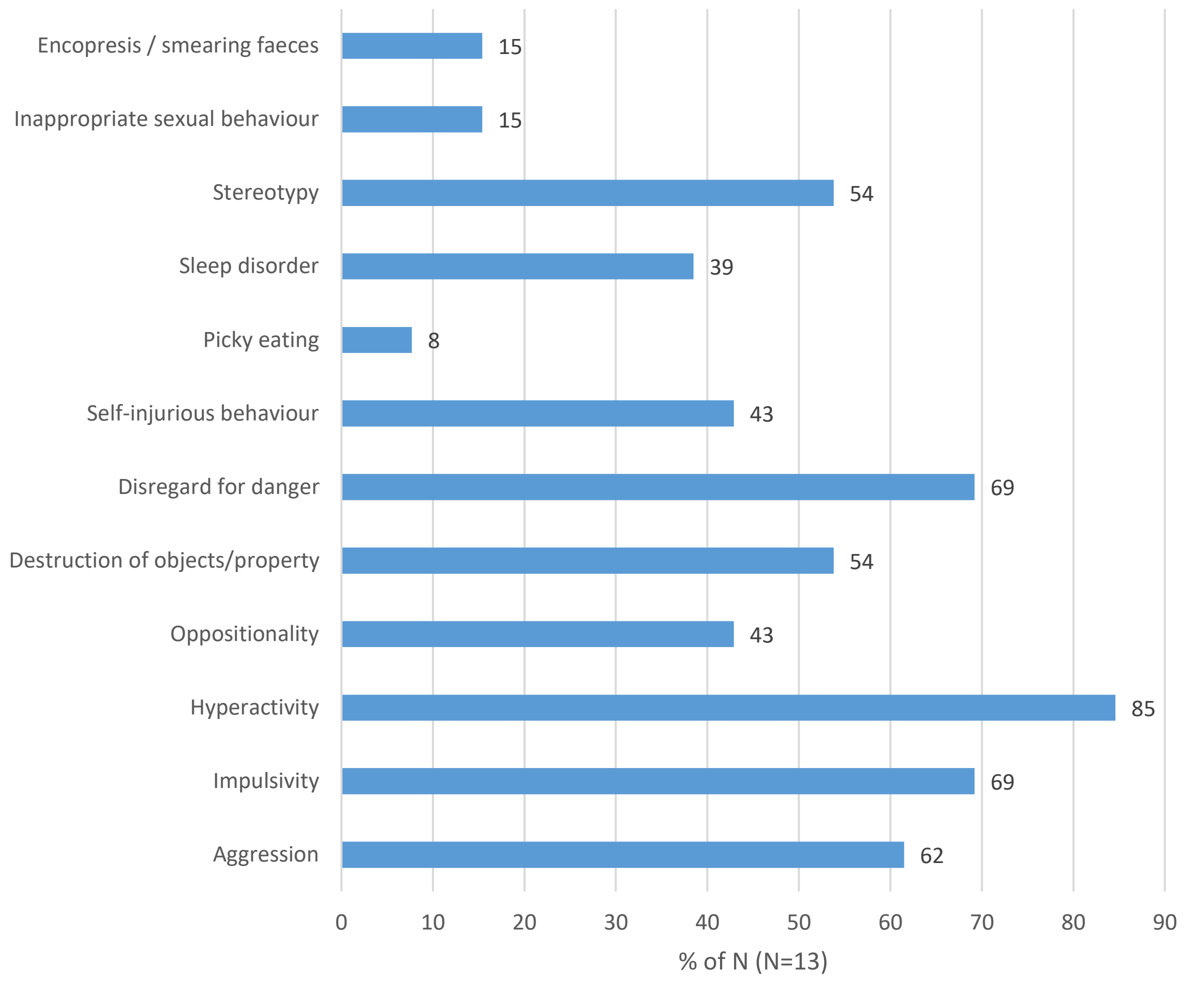
3.2.2 Respite Care Admissions

The duration of stay for these 14 children across their 53 admissions, are explored in table 3.6.

Table 3.6 Duration of Stay for Respite Care Admissions

	Total number of admissions	Min duration of stay	Max duration of stay	Mean duration of stay (SD)
Male	37	3	17	11 (4)
Female	16	7	148	23 (34)
Total	53	3	148	14 (19)

Figure 3.17 Behaviour Topographies Found During Respite Admissions



N=13 as the information describing the behaviour for one child was missing.

Table 3.7 Skills descriptions for children admitted for respite care

Skill	**Profile**	**N = 13**	**% of N**
Speech	None	6	46,2
	Single words	4	30,7
	Phrase Speech	3	23,1
	Full sentences	0	0
Feeding	No attempt	0	0
	Fingers	2	15,4
	Uses a utensil	11	84,6

Toileting	No indication of needs	2	15,4
	Some indication	0	0
	Some continence achieved	1	7,7
	Mostly continent	4	30,8
	Independently continent	6	46,2
Play	No interests	1	7,7
	Fixed interests	9	69,2
	Appropriate*	3	23,1
Interaction in groups	None	6	46,2
	Some	4	30,8
	Appropriate*	3	23,1

*Appropriate for developmental age.

3.3 Outcomes for Children Admitted for Assessment

3.3.1 Overall Behavioural and Skills Outcomes

Outcomes are presented here as the proportion of children who improved in each behavioural topography or field of skills. Numbers in bold indicate the topographies where more than 50% of children with the behaviour or skills deficit, showed clinical improvement.

The table shows that improvements were recorded for all the different behavioural topographies and all of the skills deficits encountered. 50% or more of children admitted with aggression, impulsivity, hyperactivity, oppositionality, destruction of property, sleep disorders, and encopresis/smearing of faeces, showed clinical improvement during admission. Other behaviours were more resistant to treatment. Improvements in verbal abilities (speech) were seen in the least amount of children, but skills related to toileting behaviour, play and interaction with others were seen to have improved in more than 50% of children during admission.

Table 3.8 Outcomes for Behavioural Disturbances of Children Admitted for Assessment

Behaviour Topography	Percentage Improved (number of cases showing the behaviour at admission)
Aggression	**56,1% (41)**
Impulsivity	**50% (52)**
Hyperactivity	**65,3% (49)**
Oppositionality	**56,5% (23)**
Destruction of objects/property	**56% (25)**
Disregard for danger	40,9% (22)
Self-injurious behaviour	41,2% (17)
Picky eating	21,4% (14)
Sleep disorder	**86,7% (15)**
Stereotypy	19,4% (36)
Inappropriate sexual behaviour	25% (12)
Encopresis / smearing faeces	**50% (10)**

Table 3.9 Outcomes for Skills Deficits of Children Admitted for Assessment

Skill	**Percentage Improved (n=72)**
Speech	23,6%
Feeding	47,2%
Toileting	**50%**
Play	**52,8%**
Interaction	**54,2%**

3.3.2 Comparison of Outcomes to Different Independent Variables

1. Level of Intellectual Disability

The assessment group is stratified into mild, moderate and severe ID, according to documented level of intellectual disability – no child was admitted for assessment during the study period with a diagnosis of profound ID.

Table 3.10 Comparison of behavioural outcomes between different levels of ID

Behaviour Topography	**Mild (N= 9)**		**Moderate (N=38)**		**Severe (N=27)**		**Chi Sq**	**P-value**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Improved**	**Not improved**		
Aggression	5	2	7	9	11	4	3.263	0.196
Impulsivity	5	2	11	11	10	11	1.255	0.534
Hyperactivity	3	1	17	8	12	7	0.250	0.882
Oppositionality	3	1	6	4	4	4	0.696	0.706
Destruction of objects/property	3	1	5	5	6	3	0.958	0.619
Disregard for danger	1	0	5	4	3	8	3.017	0.221
Self-injurious behaviour	2	1	0	3	5	4	3.393	0.183
Picky eating	1	1	2	6	0	4	2.121	0.346
Sleep disorder	1	0	1	2	11	0	**9.231**	**0.010***
Stereotypy	2	2	0	15	5	11	**7.266**	**0.026***
Inappropriate sexual behaviour	0	1	1	7	2	1	3.778	0.151
Encopresis / smearing faeces	1	0	1	4	3	1	3.800	0.150

* P < 0.05

Table 3.11 Comparison of skills outcomes between different levels of ID

	Level of ID							
Skill	**Mild (n = 9)**		**Moderate (n = 37)**		**Severe (n=26)**		**Chi Sq**	**P-value**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Improved**	**Not Improved**		
Speech	1	8	11	26	5	21	1.824	0.402
Feeding	4	5	16	21	14	12	0.721	0.697
Toileting	6	3	20	17	10	16	2.628	0.269
Play	5	4	20	17	13	13	0.133	0.936
Interaction	6	3	20	17	13	13	0.748	0.688

There is significant evidence that children with severe ID showed the most improvements in sleep disorders, and that children with moderate ID were less likely to improve their stereotypical behaviours than children on either side of the spectrum. These results have to be interpreted with caution, as the sample sizes are very small.

2. Gender

Table 3.12 Comparison of behavioural outcomes between girls and boys

Behaviour Topography	**Female (N=19)**		**Male (N=55)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Aggression	4	7	19	8	3,783	0,052	0,073
Impulsivity	5	10	21	14	2,991	0,084	0,124
Hyperactivity	5	6	27	10	2,889	0,089	0,144
Oppositionality	2	7	11	2	8,564	**0,003**	**0,007***
Destruction of objects/property	2	6	12	3	6,626	**0,010**	**0,023***
Disregard for danger	1	3	8	9	0,643	0,422	0,603
Self-injurious behaviour	2	5	5	3	1,727	0,189	0,315
Picky eating	0	2	3	9	0,636	0,425	1,000
Sleep disorder	3	1	10	1	0,642	0,423	0,476
Stereotypy	2	10	5	18	0,127	0,722	1,000
Inappropriate sexual behaviour	2	5	1	4	0,114	0,735	1,000
Encopresis / smearing faeces	2	0	3	5	2,500	0,114	0,444

* $P < 0.05$

Table 3.13 Comparison of skills outcomes between girls and boys

Skill	**Female (N=19)**		**Male (N=53)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	6	13	11	42	0,909	0,341	0,359
Feeding	8	11	26	27	0,271	0,603	0,789
Toileting	10	9	26	27	0,071	0,789	1,000
Play	8	11	30	23	1,180	0,277	0,299
Interaction	8	11	31	22	1,512	0,219	0,286

Interpreted with caution, there seems to be some evidence that boys showed significant improvement in destructiveness and oppositionality. There were no evidence of any other gender differences, however a larger study may obtain different results.

3. Age

Table 3.14 Comparison of behavioural outcomes between different age groups

Behaviour Topography	**5-7 years (N=34)**		**8-10 years (N=30)**		**11-13 Years (N=10)**		**Chi Square**	**P-value**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Improved**	**Not Improved**		
Aggression	7	6	12	8	4	1	1.039	0.595
Impulsivity	7	10	15	11	4	3	1.210	0.546
Hyperactivity	13	7	14	8	5	1	0.866	0.648
Oppositionality	1	2	7	5	5	2	1.267	0.531
Destruction of objects/property	0	2	10	7	4	0	5.712	0.057
Disregard for danger	3	7	3	4	3	1	2.363	0.307
Self-injurious behaviour	0	1	6	6	1	1	0.938	0.626
Picky eating	1	7	1	3	1	1	1.379	0.502
Sleep disorder	5	1	5	1	3	0	0.577	0.749
Stereotypy	0	14	4	10	3	4	**6.429**	**0.040***
Inappropriate sexual behaviour	0	4	2	4	1	1	2.222	0.329
Encopresis / smearing faeces	2	3	3	2	0	0	-	-

* $P < 0.05$

The oldest group of children showed statistically the best amount of improvement in stereotypical behaviour, with decreasing improvements with decreasing age. It could then be expected that the younger children are less likely to improve their stereotypies.

Table 3.15 Comparison of skills outcomes between different age groups

Skill	**5-7 years (N=33)**		**8-10 years (N=30**		**11-13 years (N=9)**		**Chi sq**	**P-value**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Improved**	**Not Improved**		
Speech	12	21	4	26	4	5	5.579	0.061
Feeding	18	15	12	18	2	7	3.404	0.182
Toileting	22	11	13	17	2	7	**6.928**	**0.031***
Play	17	16	16	14	5	4	0.053	0.974
Interaction	18	15	16	14	5	4	0.017	0.991

* P < 0.05

4. Autism Spectrum Disorders

It seems from the results below that the presence of ASD had very little impact on the outcomes of admissions. This may be comforting to parents, and may challenge the expectation that children with ASD have worse outcomes regarding efforts toward behavioural change when compared to their intellectual equivalents without ASD.

Table 3.16 Comparison of behavioural outcomes between children with and without ASD

Behaviour Topography	**ASD Group (N=37)**		**Non-ASD Group (N=37)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Aggression	13	6	10	9	0,991	0,319	0,508
Impulsivity	15	11	11	13	0,703	0,402	0,572
Hyperactivity	22	8	10	8	1,600	0,206	0,226
Oppositionality	10	3	3	6	4,180	**0,041**	0,079
Destruction of objects/property	10	2	4	7	5,316	**0,021**	**0,036***
Disregard for danger	6	8	3	4	0,000	1,000	1,000
Self-injurious behaviour	6	4	1	4	2,143	0,143	0,282
Picky eating	2	10	1	1	1,131	0,287	0,396
Sleep disorder	10	1	3	1	0,642	0,423	0,476

Stereotypy	7	21	0	7	2,188	0,139	0,301
Inappropriate sexual behaviour	3	6	0	3	1,333	0,248	0,509
Encopresis / smearing faeces	4	5	1	0	1,110	0,292	1,000

* P < 0.05

Table 3.17 Comparison of skills outcomes between children with and without ASD

Skill	**ASD Group (N=37)**		**NASD Group (N=35, 2 missing)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	7	30	10	25	0,929	0,335	0,410
Feeding	17	20	17	18	0,050	0,824	1,000
Toileting	15	22	21	14	2,724	0,099	0,157
Play	17	20	21	14	1,425	0,233	0,249
Interaction	17	20	22	13	2,072	0,150	0,165

5. Attention Deficit Hyperactivity Disorder

It is interesting to note from the results below that children diagnosed with ADHD prior to admission, were more likely to improve in impulsivity and disregard for danger. The implication of this is not clear. It also points to the symptom "disregard for danger" as part of the "impulsivity"-spectrum, highlighting the danger of trying to combine behaviours statistically to formulate more concise results.

Table 3.18 Comparison of behavioural outcomes between children with and without ADHD

Behaviour Topography	**ADHD Group (N=20)**		**Non-ADHD Group (N= 54)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	

Aggression	9	6	14	9	0,003	0,957	1,000
Impulsivity	12	4	2	32	25,782	**0,000**	**0,000***
Hyperactivity	14	6	18	10	0,171	0,679	0,763
Oppositionality	7	2	6	7	2,200	0,138	0,203
Destruction of objects/property	8	3	6	6	1,245	0,265	0,400
Disregard for danger	6	2	3	10	5,452	**0,020**	**0,032***
Self-injurious behaviour	1	2	6	6	0,268	0,605	1,000
Picky eating	1	0	2	11	3,949	0,047	0,214
Sleep disorder	2	1	11	1	1,298	0,255	0,371
Stereotypy	2	4	5	23	0,724	0,395	0,580
Inappropriate sexual behaviour	1	3	2	6	0,000	1,000	1,000
Encopresis / smearing faeces	0	1	5	4	1,111	0,292	1,000

* $P < 0.05$

Table 3.19 Comparison of skills outcomes between children with and without ADHD

Skill	**ADHD Group (N=20)**		**Not ADHD Group (N=52)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	4	16	13	39	0,200	0,655	0,764
Feeding	7	13	27	25	1,660	0,198	0,292
Toileting	8	12	28	24	1,108	0,293	0,430
Play	12	8	26	26	0,580	0,446	0,599
Interaction	13	7	26	26	1,309	0,253	0,299

6. Epilepsy

Table 3.20 Comparison of behavioural outcomes between children with and without epilepsy

Behaviour Topography	**Epilepsy (N=28)**		**No Epilepsy (N=46)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Aggression	10	6	13	9	0,045	0,832	1,000
Impulsivity	9	9	17	15	0,045	0,832	1,000
Hyperactivity	8	6	24	10	0,807	0,369	0,503
Oppositionality	6	7	7	2	2,200	0,138	0,203
Destruction of objects/property	5	5	9	4	0,878	0,349	0,417
Disregard for danger	3	4	6	8	0,000	1,000	1,000
Self-injurious behaviour	1	4	6	4	2,143	0,143	0,282
Picky eating	0	1	3	10	0,294	0,588	1,000
Sleep disorder	5	1	8	1	0,960	0,756	1,000
Stereotypy	3	8	4	20	0,530	0,466	0,652
Inappropriate sexual behaviour	1	13	2	6	1,378	0,240	0,527
Encopresis / smearing faeces	1	0	4	5	1,111	0,292	1,000

Table 3.21 Comparison of skills outcomes between children with and without epilepsy

Skill	**Epilepsy (N=27)**		**No Epilepsy (N=45)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	6	21	11	34	0,046	0,830	1,000
Feeding	12	15	22	23	0,134	0,715	0,809
Toileting	13	14	23	22	0,059	0,808	1,000
Play	14	13	24	21	0,015	0,903	1,000
Interaction	15	12	24	21	0,034	0,855	1,000

Epilepsy is a risk factor for the development of challenging behaviour, however there is no evidence that the presence of epilepsy influenced the outcome of admissions aimed at reducing challenging behaviour and improving skills.

7. Attendance at an Educational Facility

Outcomes for children who are attending an educational facility (of any kind) are compared to outcomes for children who are not in attendance. The "Not Attending" category includes all children who have not been attending an educational facility for more than a month prior to admission and children who have never attended an educational facility. The distribution and reasons for not attending has been explored above.

Table 3.22 Comparison of behavioural outcomes between children who are attending an educational facility and children who are not attending

Behaviour Topography	**Still Attending (N=39)**		**Not Attending (N=35)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Aggression	10	12	13	3	4,968	**0,026**	**0,043***
Impulsivity	13	16	13	8	1,423	0,233	0,265
Hyperactivity	16	10	16	6	0,671	0,413	0,542
Oppositionality	4	6	9	3	2,764	0,096	0,192
Destruction of objects/property	6	5	8	4	0,354	0,552	0,680
Disregard for danger	2	5	7	7	0,875	0,350	0,642
Self-injurious behaviour	4	6	3	2	0,291	0,590	1,000
Picky eating	2	5	1	6	0,424	0,515	1,000
Sleep disorder	5	1	8	1	0,096	0,756	1,000
Stereotypy	2	13	5	15	0,729	0,393	0,672
Inappropriate sexual behaviour	0	6	3	3	4,000	0,460	0,182

Encopresis / smearing faeces	0	1	5	4	1,111	0,292	1,000

* P < 0.05

Table 3.23 Comparison of skills outcomes between children who are attending an educational facility and children who are not attending

Skill	**Still Attending (N=37)**		**Not Attending (N=35)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	3	34	14	21	10,143	**0,001**	**0,002***
Feeding	12	25	22	13	6,680	**0,010**	**0,018***
Toileting	16	21	20	15	1,390	0,238	0,346
Play	15	22	23	12	4,573	**0,032**	**0,037***
Interaction	16	21	23	12	3,658	0,056	0,064

* P < 0.05

8. Primary Care Giver

Outcomes for children who are cared for by both their biological parents in the same house, are compared to children who are cared for in fragmented families. The category “other” has been chosen to encompass all children who are cared for by a single parent, family members other than their biological parents, unrelated foster parents, or within institutions.

Table 3.24 Comparison of behavioural outcomes between children who have both biological parents at home and children who have other primary care givers

Behaviour Topography	**Both Parents (N=28)**		**Other (N=46)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	

Aggression	8	9	15	6	2,335	0,126	0,185
Impulsivity	8	12	18	12	1,923	0,166	0,248
Hyperactivity	10	8	22	8	1,600	0,206	0,226
Oppositionality	5	6	8	3	1,692	0,193	0,387
Destruction of objects/property	6	6	8	3	1,245	0,265	0,400
Disregard for danger	2	8	7	4	4,073	0,044	0,080
Self-injurious behaviour	4	4	3	4	0,077	0,782	1,000
Picky eating	2	7	1	4	0,009	0,923	1,000
Sleep disorder	6	1	7	1	0,010	0,919	1,000
Stereotypy	3	12	4	16	0,000	1,000	1,000
Inappropriate sexual behaviour	0	7	3	2	5,600	**0,018**	**0,045***
Encopresis / smearing faeces	1	2	4	2	0,900	0,343	0,524

* P < 0.05

Table 3.25 Comparison of skills outcomes between children who have both biological parents at home and children who have other primary care givers

Skill	**Both Parents (N=27)**		**Other (N=45**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	1	26	16	29	9,492	**0,002**	**0,002***
Feeding	10	17	24	21	1,798	0,180	0,226
Toileting	10	17	26	19	2,904	0,088	0,144
Play	11	16	27	18	2,511	0,113	0,146
Interaction	12	15	27	18	1,645	0,200	0,229

* P < 0.05

9. Type of Residence

Two categories were chosen from the collected data. Due to the small amount of children (6) who lived either in rural settlements or institutions, these results were excluded from the correlation calculations, leaving 68 children. The remaining two categories are thought to denote the difference in socio-economic circumstances between children living in urban informal dwellings and children living in formal residential dwellings. However, the nature of socio-economic circumstances in the greater Cape Town area is such that the difference between living in an over-crowded house with inside toilet, and living in a one-room dwelling constructed from corrugated iron with outside public toilets, is not very much.

Table 3.26 Comparison of behavioural outcomes between children who live in informal urban housing structures and children who live in formal urban housing

Behaviour Topography	**Informal Housing (N=27)**		**Formal Housing (N=39)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Aggression	9	3	11	9	1,280	0,258	0,452
Impulsivity	9	6	13	12	0,242	0,622	0,747
Hyperactivity	13	3	14	13	3,716	0,054	0,101
Oppositionality	4	2	8	5	0,046	0,829	1,000
Destruction of objects/property	4	2	7	5	0,117	0,732	1,000
Disregard for danger	3	6	4	4	0,486	0,486	0,637
Self-injurious behaviour	2	1	5	4	0,114	0,735	1,000
Picky eating	1	5	1	6	0,014	0,906	1,000
Sleep disorder	4	1	6	0	1,320	0,251	0,455
Stereotypy	2	11	3	14	0,027	0,869	1,000
Inappropriate sexual behaviour	2	2	1	5	1,270	0,260	0,500
Encopresis / smearing faeces	2	3	3	2	0,400	0,527	1,000

Table 3.27 Comparison of skills outcomes between children who live in informal urban housing structures and children who live in formal urban housing

Skill	**Informal Housing (N=26)**		**Formal Housing (N=38)**		**Pearson's Uncorrected**		**Fischer Exact P**
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**p-value**	
Speech	9	17	5	33	0,229	0,632	0,748
Feeding	11	15	18	20	0,160	0,690	0,800
Toileting	14	12	17	21	0,513	0,474	0,611
Play	15	11	16	22	1,502	0,220	0,309
Interaction	15	11	17	21	1,036	0,309	0,446

10. Verbal Communication Ability

Table 3.28 Comparison of behavioural outcomes between different levels of verbal communication ability

Behaviour Topography	**No words (N=29)**		**Single Words (N=29)**		**Phrase or Full Speech (N=16)**			
	Improved	**Not improved**	**Improved**	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**P-value**
Aggression	7	6	10	5	6	4	0.4807	0.7863
Impulsivity	9	10	9	9	8	5	0.6660	0.7168
Hyperactivity	13	8	11	5	8	3	0.4274	0.8076
Oppositionality	3	4	6	4	4	1	1.6708	0.4337
Destruction of objects/property	4	6	6	2	4	1	3.2675	0.1952
Disregard for danger	2	7	5	4	2	1	2.8519	0.2403
Self-injurious behaviour	3	4	3	3	1	1	0.0765	0.9625
Picky eating	1	3	1	7	1	1	1.3788	0.5188
Sleep disorder	7	0	6	2	0	0	-	-
Stereotypy	3	12	3	11	1	5	0.0595	0.9707
Inappropriate sexual behaviour	1	3	2	2	0	4	2.6667	0.2636
Encopresis / smearing faeces	2	1	2	2	1	2	0.6667	0.7165

Table 3.29 Comparison of skills outcomes between different levels verbal communication ability

Skill	**No words (N=27)**		**Single Words (N=29)**		**Phrase or Full Speech (N=16)**			
	Improved	**Not Improved**	**Improved**	**Not Improved**	**Improved**	**Not Improved**	**Chi Square Test**	**P-value**
Speech	6	21	7	22	4	12	0.051	0.975
Feeding	14	13	12	17	8	8	0.679	0.712
Toileting	12	15	13	16	11	5	2.937	0.235
Play	14	13	14	15	10	6	0.852	0.653
Interaction	15	12	12	17	12	4	4.728	0.094

There is no evidence of any association between verbal ability and clinical outcomes – the sample size may have been too small.

4 DISCUSSION

This study examined the clinical records of children with intellectual disability who were admitted to a specialised unit, in order to describe the population of children who utilised this service, and to document the outcomes of these treatment programmes. Good clinical record keeping was found throughout the folders that were reviewed, as very little data was missing.

4.1 Demographic Findings

During the study period, 88 children aged 5 to 13 with intellectual disability were admitted, some of them multiple times. The male to female ratio was 3:1. Indication for admission was either assessment and management of behaviour (74 single admissions), or respite care (14 children admitted multiple times). The mean age for assessment was 8,62 years (SD 2.06), and that for the respite group was about 2 years older - with mean age 10.96 years (SD 1.67). This is expected as the admissions for respite care occur mostly as a continuation of care subsequent to admissions for assessment.

Half of the group (51%) had a diagnosis of moderate ID, and 34% had severe ID. 14% had mild ID and the remaining 1% had profound ID. The diagnosis of profound ID was not encountered among children with disruptive challenging behaviour, possibly due to the high rate of physical disability that accompanies this diagnosis.

The aetiology of intellectual disability in these children with challenging behaviour was as complex as the presentation. Some had well-documented aetiology, while others had confounders that were reported by a care giver that was often not the biological mother. In 41% no clear reason was found and this is comparable to data from across the world. Of the children with known aetiology, 14% had causes that were not preventable. Of these, 13% had known genetic syndromes, including Down, Fragile-X, Kabuki, Dandy Walker, Rubenstein-Taybi, Rett and tuberous sclerosis. Most of these genetic syndromes are known to be associated with behavioural phenotypes. One child had a cerebral tumour (a craniopharyngioma).

The remaining 45% of children with known aetiology, had causes that were potentially preventable. This correlated with the high burden of preventable causes of ID in South Africa as noted by Adnams.(8) Perinatal complications (22%) were defined as any event complicating the birth of the child – it could be reported on as caesarean section for foetal distress, low Apgar scores at birth, premature birth, or having been treated in ICU after birth, etc. Foetal alcohol spectrum disorders (FASD) were suspected in 11%. This was consistent with the high prevalence of FASD in the Western Cape – exact statistics are still unknown but a conservative estimate is 14/1000 across South Africa, with the highest prevalence reported in one area of up to 119/1000 school aged children(34). Meningitis was stated as the cause of ID in 10%. Of the 9 children who had meningitis in infancy, 4 had tuberculous meningitis. There was one child with a traumatic brain injury (suspected non-accidental), and one who survived septic shock other than meningitis in infancy.

Aetiological confounders were present in many cases. For instance, a child may be captured as aetiology unknown, but he has dysmorphic facial features. Another child may have perinatal complications as the main diagnoses that are described in his notes as premature birth, but according to the foster parent, the biological mother also used illicit substances during pregnancy and attempted a home abortion. In a cascade of misfortune this child, who is clearly unwanted, is then born into a chaotic home where he is possibly abused, probably neglected and eventually removed and placed into the care of a stranger, or handed from one family member to another, having no chance in forming a secure primary attachment. The child's developing brain undergoes insult upon insult, and where the premature birth alone predisposed him to perhaps a learning disability, the compounding effect of all the adverse events subsequent to birth is responsible for the severity of the intellectual deficit.

One or more psychiatric comorbidity was found in 68% of children (50 of 74) admitted for assessment, and 100% of children admitted for respite. Combining these two groups, the prevalence for any psychiatric disorder amongst the study group, is 72%. This is significantly higher than the 31% reported by Molteno et al(10) among children in schools for LSEN in Cape Town. This author is of the opinion that the prevalence of psychiatric disorders in this study population is even higher, and that it is under-recorded in the patient records, perhaps in an effort to avoid labelling a child with a diagnoses that has long term implications but no easy solutions. For instance, diagnoses such as reactive or disinhibited attachment disorders are often talked about and even addressed in therapy, yet in only one child was this recorded as part of his comprehensive diagnoses. Another psychiatric diagnosis that lacks presentation in this study group, is anxiety – only 5% of the study group had a formal diagnosis of generalised anxiety disorder (GAD). The prevalence of anxiety is especially high amongst children with ID and ASD who are unable to speak according to Molteno et al.(10), and this was noted by Emerson & Einfeld(4) to be a risk factor for developing challenging behaviour. A further reason to the difficulty in recognising specific psychiatric symptoms in children who are unable to report their thought content, either due to their level of ID, or their verbal limitations. Siegel(15) also discusses the difficulty of accurately identifying comorbid psychiatric disorders in children with ID, but that it is an important component of targeted treatments that will lead to better outcomes. Siegel suggests a process of utilizing expert consensus based upon extended inpatient observation, to arrive at these diagnoses. If one was to investigate the psychiatric comorbid diagnoses in this study population pre- and post-admission, one would probably find that the prevalence does increase, as is indicated by the high prevalence of diagnoses in children being admitted for respite care.

58% of all children admitted over the study period had one or more chronic physical condition. In line with international figures, 36% of this subset of children with ID also suffers from epilepsy. It is well known that chronic medical and physical conditions contribute to behavioural problems not only children with intellectual disability, but also their neurotypical peers. In fact, Emerson & Einfeld(4) dedicate a whole chapter to the influence of biological factors on developing challenging behaviour.

To illustrate the complex interplay between aetiological factors of challenging behaviour, consider the case of an 8 years old boy. He had a diagnoses of severe ID with dysmorphic features not identified as a genetic syndrome, and was admitted for a cluster of severely dysregulated behaviour consisting of aggression (lashing out to adults, violent tantrums, screaming, spitting), hyperactivity and impulsivity, sleep problems, self-injury (severely hitting himself in the face with reflexive accuracy and regularity, or banging his head against objects or people), and anal scratching and encopresis. The behaviour was well established by the time he was admitted, as the factor that motivated his parents to seek professional help, was that they couldn’t find educational placement for him. This boy’s assessment revealed an extremely complex interplay of environmental and psychological factors, however a standard medical history also revealed recurrent tonsillitis (which was confirmed by examination), that remained untreated as it was impossible for his parents to take him to the primary care physician. Pain and malaise from tonsillitis was assessed as a contributing factor in his extreme irritability and self-injury, and his behaviour improved once adequately treated. He also received a dose of deworming agent – which is standard treatment of all children admitted to the unit – and anal scratching improved within days, however the encopresis itself was much more resistant to change.

It is important to note that the unit admits children with behavioural problems, who are medically stable, therefore the treatable medical conditions seen were low, and in the case of acute illness, children are transferred to a medical facility from where they are discharged home, to be admitted electively at a later stage, once stabilized.

Despite the high prevalence of HIV in South Africa, no children were admitted who were HIV positive, and there are very few children treated as outpatients, who are HIV positive. The reason for this is not clear, but it is thought that children who are HIV positive receive a full package of care elsewhere. It is not known at this point what the care needs are of children with ID and challenging behaviour who are also HIV positive, or whether these needs are being met by integration in other services.

Environmental risk factors for the development of challenging behaviour were high in this group. Three factors were explored, namely the type of housing that the family could afford to live in, the presence of financial aid provided by social services for the care of the child, and the care structure at home. Emerson et al. called this risk factor "Household poverty and neighbourhood deprivation."(35) Only 58% of the study population lived in a house classified as "urban formal", meaning a conventional brick house with inside water and electricity. This however gives no indication of the quality of the neighbourhood in which they live. The reality is that most of the children who live in "urban formal housing" (and all of the children living in informal settlements) would fulfil Emerson's criteria for household and neighbourhood deprivation. The housing figures also showed that children from rural areas are not accessing the service at the same rate as children from the metropolitan areas.

The poor socio-economic circumstances were further illustrated by the fact that 89% of children came from families who qualified for social financial assistance. Of these, at least, it can be noted that there was good uptake of care dependency grants.

The home circumstances of these children were complicated by fracturing of families and care structures. 21% of the study population did not have either of their biological parents at home and 35% were cared for by their single mothers. This has implications for the primary attachment of these children and its contribution to their future attachment style and subsequent behaviour.(29) The absence of a father figure is noted in many cases – these figures do not even touch on the cases where both parents are at home, but the father has distanced himself from the care of the disabled child, or where there is serious marital conflict.

Management of the child with behavioural difficulties starts at community level. For children with ID, the points of access to services are through the education and health departments. The findings showed how, despite recent drives toward equal and inclusive education in the Western Cape, 29% of the study population where not placed at an educational facility at the time of admission. For two children, it was recorded that access to schooling facilities was denied, showing misinformation and systemic break down. According to the Constitution, no child can be denied access to a school and once the education department has been accessed, it is responsible for placement. However things do go wrong and instead of these children being referred on toward appropriate placement by the mainstream facilities that were their point of entry, the care givers understood that the child could not be schooled.

It was also shown that, despite efforts toward placement, there was a high drop-out rate. At initial assessment, 30% of children had never been placed in an educational facility. Among children admitted for respite care, 100% of them had received educational placement subsequent to the initial assessment as part of their package of care. However, 31% of children receiving respite care, had dropped out of their educational placements and were being cared for at home – hinting at the challenges in managing the child, the detrimental effects of not going to school, and the lack of resources in the community to assist care givers in managing children with challenging behaviour. Would the child still need respite care if he was going to school regularly? The answers are complex and multifactorial.

Inquiry into reasons for not attending educational facilities showed that 82% of the children not attending their educational placement, were asked to rather leave the facility due to their behaviour – they were allowed to return once behaviour had improved. Behaviour that disrupted group activities, required the teacher to engage with the child much more than with other children, or endangered the child or others, were cited as reasons for suspension. Very often suspension from a facility initiated hospital admission. Some families had problems with transport to special schools – most schools do have transport services, but it is costly. Sometimes there were no appropriate facilities available in the area where the family lives, especially if they were from rural regions. In a few cases, the carer was not impressed by the care given to her child at the facility and decided to attempt home schooling.

Most children (69%) were referred from tertiary hospital neurodevelopmental services, the others were referred from various secondary and community institutions, including 22% that were referred through the education department. Tertiary services in the Western Cape are only available in Cape Town, at the two major hospitals, Red Cross Children's Memorial Hospital and Tygerberg Children's Hospital. The private sector is no better, with most of the private child psychiatrists situated in Cape Town. Presumably there is a large under-serviced community of children with behavioural problems in the rural parts of the Western Cape. They are presumably managed at community level, however very little is known about this population. Looking at the complexity of children with behavioural problems that do present, one can only speculate at the burden of care and effect of interventions at community level.

4.2 Assessment Admissions

Children admitted for assessment of challenging behaviour during the study period, numbered 74, their ages ranging from 5,57 years to 13,38 years (see table 3.1). 55 of these were boys (as showed in figure 3.1). 16% were urgently admitted for assessment due to the extreme nature of their behaviour, however none were admitted as emergencies. This is in keeping with admission protocols, where emergency presentation in children has to be assessed by the medical services first, before referral to psychiatric services. Urgent admissions were those that were referred as having extremely challenging behaviour endangering themselves or others, having depleted community resources for management, but having been cleared medically.

The average duration of stay was 46 days with a large standard deviation of 27 days. It is interesting to note that in Siegel's study(15) regarding the outcomes of this type of intervention in the USA, the average duration of stay was 45 days (SD14). The child with the longest duration of stay in Cape Town completed the 3 month assessment admission with good improvement, however the assessment showed dire social circumstances and it was not safe for him to go home. A lengthy social services intervention then took place in order to find alternative placement for him. The child with the shortest stay was prematurely discharged as his mother was uncomfortable with the idea of a lengthy admission.

Each child presented with a cluster of behavioural topographies unique to that child. The behaviour with the highest prevalence in the study group was found to be impulsivity (50 children), with 48 children recorded to have hyperactivity, and 38 with aggression. The behaviour with the lowest prevalence amongst the study group, was encopresis/smearing faeces, shown by 10 children. There was much variability as to the clustering, as well as to the different presentations of the behaviour encapsulated by each topography and the frequency of presentation. One child may have presented with impulsivity, hyperactivity, disregard for danger and picky eating; another with aggression, stereotypy, and sleep disturbances. A child with aggression may have had different expressions of aggression, e.g. lashing out to other adults or children, grabbing at others, biting others, pinching others, or hitting or throwing others with objects. Different degrees of severity of similar behaviours were also seen. One child, in a severe episode of self-injury pre-admission, bit off the distal ends of two of his toes. (He showed skin picking during his lengthy admission, none as severe as what reportedly happened at home.)

It must be reiterated here that efforts to combine clusters of behaviour into a more statistically elegant equation without the use of a validated clinical tool is futile, as the behaviours recorded in the narrative of patient records often overlap and may describe the same problem in different words and will therefore be confounders in such an equation.

A worrying number of children (16%) presented with sexually inappropriate behaviour. It is well known that children, especially children with poor verbal ability, are extremely vulnerable to sexual abuse or exploitation. However, there is also the notion of developmentally appropriate bodily exploration, as well as the fact that some of these children have limited capacity to understand social norms. One should therefore not jump to the conclusion that all of these children have been sexually molested, however a low threshold to investigation should be maintained.

The skills descriptions recorded for each child, showed the overall low level of functioning in this group. Rather than trying to be a scoring system to record functionality, it is used in the narrative describing the child’s abilities and care needs. It is important to assess behaviour against the background of basic skills, otherwise a narrative of challenging behaviour can too easily sound like the child understands the implications of his behaviour and that he therefore has a conduct disorder.

The children admitted for assessment were mostly non-verbal (39%) or using a few single words (39%). Less than a quarter were able to communicate their needs clearly with the use of phrases (16%) or full sentences (5%). This is important to note, as Emerson & Einfeld(4) explain that low verbal ability is a major risk factor to development of challenging behaviour, and a predictor towards the outcome of interventions.

Toileting and feeding behaviour were recorded as major indicators of self-care milestones. Of the children admitted, despite some children having some physical difficulties, for instance spasticity, no child had a physical disability that prevented them from being able to hold a spoon and bring it to the mouth. A few struggled to hold a conventional spoon, but soon acquired the skill once given a spoon adapted to ability (e.g. a spoon with built-up handle). In most the feeding behaviour reflected more on care-giver behaviour – some carers chose to continue spoon-feeding, other stopped trying to teach the child the use of a utensil. A school-aged child who has never been given the opportunity to learn to feed himself may stop trying and show no attempt at using a spoon, and sometimes no attempt at feeding at all. A child may also develop a secondary disability, as explained by Sinason, where lack of independence ensures the child of care giver attention.(36) A cultural consideration here is also necessary, as eating with hands is considered normal in some cultures and can explain the lack of skills when using a feeding utensil. Whatever the underlying reason for lack of attaining feeding milestones, such a child is usually cared for at home and if he does get school placement, the feeding behaviour becomes an obstacle and even a barrier to learning. The child found at school by his care giver sitting in the middle of the mess he made with a plate of food while the teacher or class assistant is busy elsewhere, may be taken out of the school with the complaint that “they did not treat him well”.

Toileting behaviour in the child with ID is problematic and controversial. For 36% of the children investigated for his report, the care giver reported that the child needs toilet training in order to be allowed to go to school. At a workshop regarding toilet training for children with ID presented by this author and MDT colleagues, it was asserted by one of the teachers who attended, that “Teachers should teach, not clean nappies!” As much as it is understood and felt that toileting skills should not be a barrier to learning, it seems that this crucial milestone is unofficially being used as a sifting measure on the long waiting lists for admission to a school for LSEN. With only 16% of the study group independently continent, the enormity of the problem with school placement becomes apparent.

Play and interaction abilities were recorded as a measure of social communicative ability. It is not used as indications of autism here, as poor play and interactive abilities are also associated with psycho-social deprivation. Less than a third of children showed play and interaction appropriate to their developmental age.

Enquiry into pharmacotherapy for children who were admitted for assessment showed 78% of children received one or more agents (average 1,3 agents), with the maximum number of agents used in one child as being 5. Risperidone, an antipsychotic drug, was widely used to ameliorate behaviour, methylphenidate used to treat hyperactivity, and anti-epileptics (mostly sodium valproate and carbamazepine) for seizure control. In 63% of children who were prescribed risperidone before admission, a lower dose with similar effect on behaviour management was found during the course of the admission. It is clear from table 3.5 that pharmacotherapy is not the mainstay of behaviour management in this population.

Very few patients were treated with anxiolytics - notably there is an absence of treatment with selective serotonin reuptake inhibitors (SSRI’s) such as fluoxetine and citalopram. These are widely used in children with ID/DD and anxiety according to Siegel et al, although with limited published evidence – perhaps due to the difficulty in establishing a validated measure of anxiety in these children.(37) The low number of children treated for pharmacologically for anxiety aligns with the observation of possible underdiagnoses of anxiety at this treatment unit or a bias against pharmacotherapy for observed anxiety. The clinical opinion at this unit is that anxiety is caused mostly by unstable environmental factors and that these should be addressed before pharmacotherapy is instituted.

4.3 Respite Care Admissions

Children admitted for respite care during the study period numbered 14, their ages ranging from 8,28 years to 13,68 years (see table 3.1). 11 of these were boys (as showed in figure 3.1). Most of these children received more than one respite care admission. The average amount of admissions for children who received respite care was 2.5. The most admissions for one child within the 2 year period of the study was 8. Only one child was admitted urgently for respite, the others followed the process for elective admissions. The average duration of stay was 14 days (SD 19 days).

The child with the longest admission had severely challenging behaviour with a single mother who was unable to cope with her care. Community resources had been exhausted and she was removed from her home by social services for reasons of safety. She was admitted under the procedure for respite care as she needed a temporary place of safety while placement options where explored. There was no other place of safety available that provided the experience and expertise needed to manage her behaviour. Her diagnoses was severe ID with autism. She was non-verbal with very poor basic skills. She exhibited self-injurious behaviour, destruction of property, inappropriate sexual behaviour, and smearing of faeces.

The behavioural profiles of the children admitted for respite care were complex with each child presenting with multiple topographies with variation between and within categories. These children were well-known to the unit and in all of them the challenging behaviour had been described as longstanding by the staff who knew them, and looking back into their records this remains true. This reflects on the natural history of challenging behaviour as it persists over time and is exacerbated by environmental stressors.

The skills description again showed the low general level of functioning of these children. None of them spoke in full sentences, and less than a quarter were able to use phrases. Most of them were able to operate a spoon, and perhaps this indicated improvement over the longer term, that is between the first admission for assessment and admission for respite care a few years down the line. Similarly almost half (46%) was independently continent and a further 30% was mostly continent if supervised. Play and interaction appropriate to developmental age remained low (23% each).

There is a great need for community based respite care services for children with challenging behaviour, as psychiatric hospitalisation for respite is not the ideal use of resources. However, the community need is reflected in the number of applications received by this service, and the report from care givers regarding their inability to find community based services. A separate enquiry into the magnitude of this is needed.

4.4 Treatment Outcomes and Associated Risk Factors

The significance of these outcomes for behaviour and skills cannot be commented on, as there is no control group. However, they are important to note, because for most of these children this was a last resort effort to improve their social functioning. It is clear from the above tables that clinical improvement was seen in all behavioural and skills spheres.

Behaviourally, the largest number of improvements were seen in sleep disorders (87% improved) and hyperactivity (65% improved). Third was improvements in aggression, oppositionality and destruction of property.

The finding regarding sleep disorders is interesting. It is not the usual practice of the unit to provide sedatives at night and sleep is encouraged through strict routine and gentle nursing measures. It is possible that the reporting is biased by the nursing staff who evaluate the progress, as they are night shift workers who possibly have a higher tolerance towards children waking at night than an exhausted mother might have. It might be reported by the night staff the child woke three times during the night and went back to sleep after some gentle encouragement. However when the mother reports on the same situation happening at home, she would say that she is exhausted from the child waking up all the time and that the only way he would fall asleep is if she lets him sleep in her bed. It is also frequently the opinion of the clinical staff that the sleep problems experienced at home are the result of a lack of consistency in parenting, lack of household routine, and high emotional arousal within the household.

Stereotypical behaviours seemed least amenable to therapies applied during the admission, and this is important, as almost half of all children admitted showed some form of stereotypical behaviour. It is also an expected finding, as stereotypical behaviour is a core feature of ASD and also a common finding in children with ID.

Improvements in skills were also seen across all fields, with the most improvements seen in play and interaction, and the least number of improvements in verbal communication.

When comparing different independent variables to the clinical outcomes recorded for each behaviour and skill, there were a few significant findings. Interpretation of these findings must be cautious in all instances due to the small sample sizes and due to the inability to control for confounding factors.

The level of ID seemed to have an influence on outcomes for sleep disorders and stereotypy. Individuals with worsening levels of ID seemed to have better outcomes with sleep disorders, with all of the individuals with severe ID who presented with sleep disorders, being improved by discharge. Individuals with stereotypy did not show any improvement if they had moderate ID, but if their ID was in the mild range, half of them improved.

There was some evidence that boys with destructiveness and oppositionality were more likely to improve within those topographies than girls.

Chronological age seemed to influence improvement in stereotypical behaviour in a linear fashion, with older children being more likely to improve than younger children. Improvement in stereotypies however remained low across all age groups. There is also a statistically significant association between improving toileting skills and age group. The youngest group showed the greatest number of improvements, the middle group showed less improvements, and the oldest group showed the least number of improvements. This might mean that the older children have mostly achieved their self-care skills and little improvement can be expected in these groups.

There was some evidence to show that children with ASD improved significantly in the areas of oppositionality and destructiveness. There was no evidence that ASD had a significant influence on acquiring basic skills, however one could speculate that if numbers were higher, the core difficulties of ASD (a deficit in social communication) would show in a failure to improve play and interaction.

There was a marked improvement in impulsivity and disregard for danger amongst children who carried an ADHD diagnosis, despite not having significant improvement in hyperactivity. There was no evidence of an association between improvement of basic skills and the existence of ADHD, despite its reputation as being a stumbling block towards reaching basic self-care mile stones.

There was no significant correlation between the diagnoses of epilepsy and the behavioural or skills outcomes. This is an important finding that can be viewed in the light of the results of prescribed medications for the study population. Referring back to Table 3.5, it can be noted that only three children had an anti-epileptic agent added to their treatment regime after admission and a 36% prevalence of epilepsy was found in this population (Figure 3.5) which was in line with international figures of epilepsy in people with ID. Challenging behaviour was not found to occur more frequently in children with ID and epilepsy than those without epilepsy, as reported by Molteno et al(10). This means that despite epilepsy being a risk factor for the development of challenging behaviour, once epilepsy is controlled, it has no further effect on the natural history of challenging behaviour. It also reflects on the current status of children with ID and challenging behaviour who also have epilepsy, and that they are receiving treatment.

Children who were not attending an educational facility were shown to have significant improvements in aggressive behaviour (p=0,026). Parental disciplinary style could be implicated by this result, however more information is needed. Basic skills in communication, feeding and play were seen to be significantly improved (with a trend towards improving interaction as well) among children who did not attend an educational facility. Interestingly toileting skills were not significantly improved among children who are not attending a facility, despite the notion that some children were admitted “just for potty training.” Further investigation is needed, however these results concur with the general idea that all children should be afforded equal opportunity to attend an educational facility, and they should not be excluded due to problems with self-care. Toileting skills are important developmental milestones and not mental health care problems, unless it can be shown to be behavioural enuresis or encopresis.

The different categories of care structure did not yield remarkable results. It seemed that children who were living with both biological parents were less likely to improve in speech. Interestingly, or maybe alarmingly, inappropriate sexualised behaviour is significantly less likely to improve if a child lives with both biological parents. Perhaps the categories of care structure were not sensitive enough to be a variable indicating home circumstances. The presence of marital conflict may be a major confounder that is not controlled for.

There was no evidence for an association between the type of housing that the children grew up in, and the outcome of behaviour and skills interventions. This strengthens the notion that housing structure as an independent variable is not sensitive enough to detect its influence on the intervention outcomes.

There was no evidence for the effect of verbal ability on clinical outcomes. This may be because there was very little improvement in communication abilities across admissions. It is thought that the addition of a speech and language therapist to the treatment team may address communication difficulties and in turn this may lead to improved outcomes for children who respond to augmented communication strategies.

5 CONCLUSION AND RECOMMENDATIONS

The aims of this study were met in that this report provides the first audit of inpatient services for children with ID in South Africa. The study therefore provides a baseline description for a group of patients who received a systematic short term multidisciplinary inpatient intervention, as well as the outcomes of these inpatient interventions.

The strengths of this study are that this research is original for South Africa and it showed that the record keeping in the unit evaluated was good. The study's weaknesses are the lack of control group, a possible selection bias, the lack of use of an objective clinical tool to evaluate the progress of children under treatment and the possible bias arising within the opinions of the treating clinicians, the binary nature of reporting treatment outcomes that give no indication of the size of change or the clinical significance thereof, and the small study size.

It was shown that challenging behaviour was the overarching indication for admission and the key findings were that clinical improvement was recorded in each area of clinical focus. This is highly relevant since admission to this treatment program implied that all prior interventions had failed, if they were applied at all. Importantly, it also showed that neither the presence of autism spectrum disorders, nor the presence of epilepsy, influenced the outcomes for interventions aimed at improving challenging behaviour in this population. Many findings were consistent with those published from studies done in high income countries.

The importance of low socio-economic circumstances in the development of challenging behaviour was emphasized by the description of demographical features of this study population. This has important implications for planning for the provision of services for the prevention and treatment of challenging behaviour in children with ID, in middle to low-income countries.

From the findings in this study, the following recommendations can be made:

1. Given that there were improvements across all topographies of challenging behaviour through inpatient treatment, an effort should be made to establish the time to improvement, as well as an indication of the size of the improvement, in order to optimise length of admission and to set realistic outcome goals.

2. The treatment model followed at the unit can be optimized to align with the consensus statements on best practices of psychiatric hospitalization for children with ASD or ID, as published by the ADDIRC(25).
3. A standardised clinical tool, such as the ABC, SDQ or CGI, should be used routinely in each patient at standard intervals during admission, to document progress and optimise treatment duration. This will also ensure systematic and continual production of the "practice-based evidence generated from routine practice" that Emerson and Einfeld(4) call for.
4. The clinical meaningfulness and sustainability of outcomes should be investigated in a prospective study utilizing standardised clinical tools to document behavioural profiles and change.
5. As a large number of study participants (50%) had a duel diagnosis of ID and ASD, members of the MDT should receive specific training in the care and management of children with ASD, and the service should actively collaborate with community organisations for the support of families of children with ASD.
6. Given the importance of communication in this population, speech and language therapists should be included in all IDS MDTs
7. Opportunities for community based respite care should be investigated and promoted as part of community support for families caring for children with ID and challenging behaviour.
8. Pharmacological treatment of epilepsy in children with ID and challenging behaviour should continue to receive priority, and persisting challenging behaviour in a child with well-controlled epilepsy, should be fully investigated for other contributing factors.
9. Children should not be admitted for the treatment of stereotypical behaviour only, as this responds poorly the current intervention. However, its contribution to the behavioural problem should be evaluated, bearing in mind that anxiety and agitation for any reason, can increase stereotypical behaviour.
10. The comorbid diagnosis of anxiety lacks presentation in this study population both in formal diagnoses and in pharmacological treatment. The protocol for initiating anxiolytic pharmacotherapy in these children should be reviewed and can be aided by the use of a standardised clinical tool that documents the manifestation of anxiety over time.

It is hoped that the findings and recommendations will contribute to establishing evidence based models of care for children with intellectual disability and challenging behaviour, and that it highlights the importance of providing a service for a condition that, by definition, often causes exclusion from access to ordinary community services and facilities.

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7 APPENDICES

7.1 Plagiarism Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I __Annette Elizabeth Theron______ (Student number: __1319834______) am a student registered

for the degree of _MSc Child Health – Neurodovelopmental option_ in the academic year _2017_.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: ________________________ Date: ____10 July 2017_____

7.2 Turnitin Report

Turnitin Originality Report

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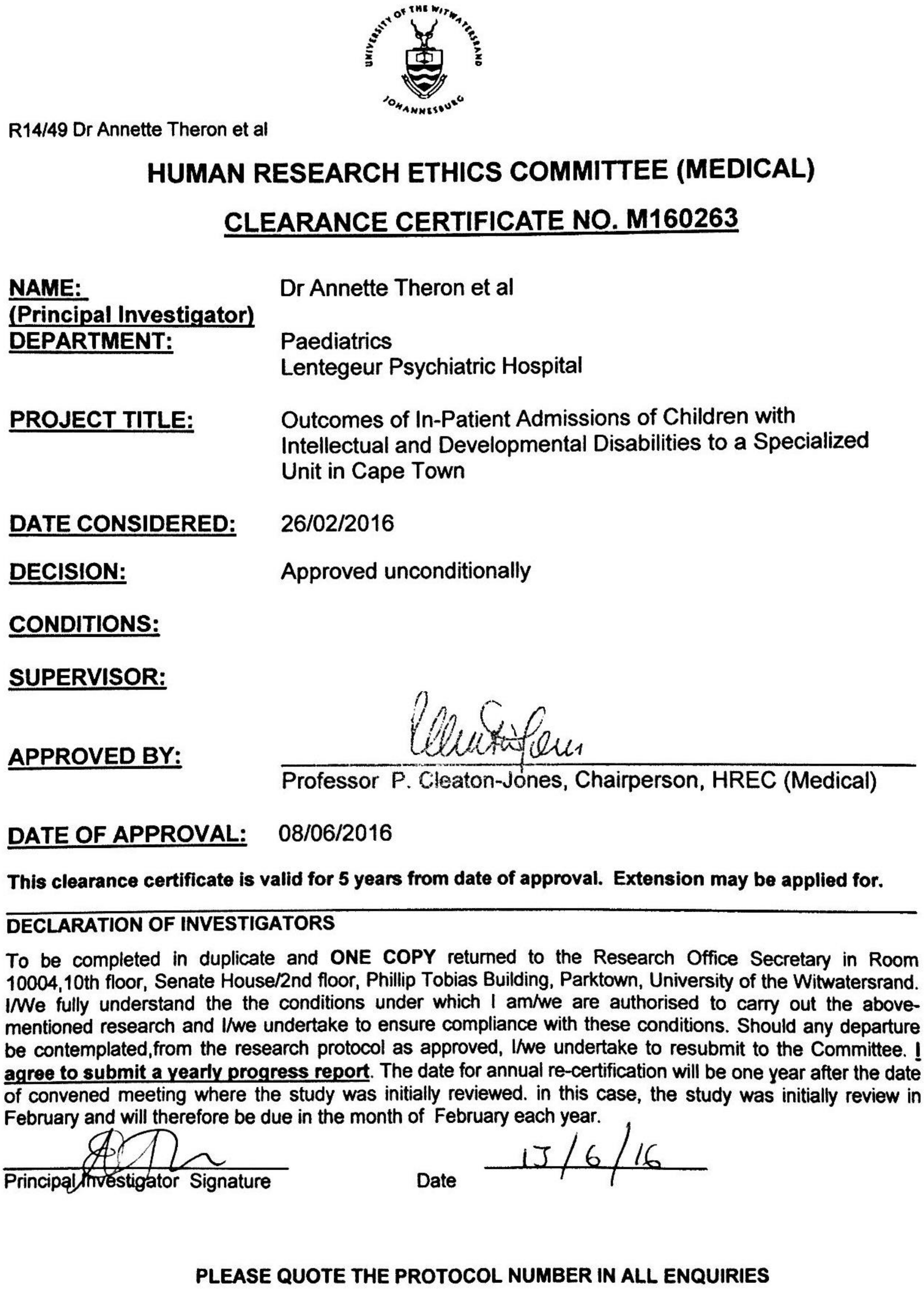
7.3 Ethics Clearance Certificate



R14/49 Dr Annette Theron et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160263

NAME: (Principal Investigator) Dr Annette Theron et al

DEPARTMENT: Paediatrics
Lentegeur Psychiatric Hospital

PROJECT TITLE: Outcomes of In-Patient Admissions of Children with Intellectual and Developmental Disabilities to a Specialized Unit in Cape Town

DATE CONSIDERED: 26/02/2016

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR:

APPROVED BY: Professor P. Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 08/06/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated,from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in February and will therefore be due in the month of February each year.

Principal Investigator Signature

Date 13/6/16

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES