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Peter's day: The Education Experience of a child with Lennox Gastaut Syndrome.

by

Velda Janet Scott

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Dissertation Tutor
Dr Eman Gaad

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Dedications

To my 'boys', Gary, Dain and Reece,
for the fetching and carrying and all the lost beach time.

To Skye,
for waiting with me.

Acknowledgements

I would like to thank all the people that helped in any way to enable me to complete this dissertation. Notably, a thank you to the staff at BUiD and my fellow students for their support and help. Special thank you, to my dissertation tutor Dr. Eman Gaad, for going beyond the call of duty. Last but not least a thank you to my family, Gary, Dain and Reece, for 'putting up' with me as well as my furry companions for keeping me company in the late hours while typing.

Poem by Gabrielle Mistral, Chilean Nobel prize winning poet. (Mittler 2000: 13)

We are guilty of many errors and many faults.

But our worst crime is abandoning the children,

Neglecting the fountain of life.

Many things we need can wait:

The child cannot.

Right now is the time his bones are being formed,

His blood is being made

And his senses are being developed.

To him we cannot answer 'tomorrow'.

His name is Today.

Abstract

This dissertation researches a unique special education need, Lennox Gastaut Syndrome ¹(LGS) within the context of the United Arab Emirates. The purpose of this research is to provide an alternative source of information regarding LGS with education in particular as the focus. The resultant aim is to promote children with LGS being educated and accepted in educational settings and to provide and develop recommendations based on this research which will facilitate future developments. The research was based on qualitative research methods where a case study approach was implemented to obtain detailed data in order to define and determine the range of possible characteristics associated with LGS and their possible affect on the education process. The actual observed characteristics of the child and understanding of the holistic realities he faces each day with the focus on the impact this has on the education process he is exposed to was examined and discussed in relation to the existing theory available and information gathered from interviews etc. Possible recommendations and strategies which can be developed to facilitate and improve on the education process of this child and other children faced with similar situations are then discussed further including aspects of inclusion relevant to this case.

On reflection at the end of the proposed research it is hoped that a contribution has been made to the field of educational research through having achieved an understanding of the holistic realities this child faces each day and the impact this has on the education process he is exposed to. In concluding this contribution opens the way forward for further studies by highlighting the need for additional research on this subject.

Key Words: Lennox Gastaut Syndrome, education, epilepsy

¹ Throughout this dissertation Lennox Gastaut Syndrome will be referred to as LGS

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1. Chapter 1 - Introduction

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To understand is hard. Once one understands, action is easy.

(Sun Yat Sen 1866-1925 cited in Cohen et al. 2000 : iii)

1.1 Introduction

Any student with exceptional or special educational needs (SEN), by definition, will require thorough assessment on many levels to enable educational provision where effective education is to be planned and made achievable. This definition will also define the context in which (the learning needs of) pupils who have been diagnosed with having Lennox Gastaut Syndrome² (LGS) will be framed. LGS is categorized in its simplest form as one of a range of possible childhood epilepsies. In reality it is "a most frustrating and devastating condition" (Freeman et al. 1997:116). While "Schools will be familiar with epilepsy" (Johnson and Thomas 1999:13), Tidman et al. states that "children with epilepsy are an educationally vulnerable group" (2003:47). In support Johnson and Thomas emphasise that "talking in general or quasimedical terms about the epilepsy does not lead to knowledge that will enhance curricula access" or "provide information which the class teacher needs to ensure the child's day to day access to the curriculum" (1999: 15,14). In this dissertation observed characteristics of an individual child with special educational needs (SEN)³ are to be determined and researched in order to identify their implications on education as related to this particular case. Further information is required to clarify Freeman's quoted view (1997:116) as well as define terminology relevant to this discussion and will be provided in the chapters to follow.

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² (Please note: LGS is a rare condition and not very researched from an educational perspective. I have therefore had to rely quite heavily on internet resources and journals, as these information mediums would be most reflective of current related issues. I have relied on my personal experience as a parent of a child experiencing LGS, interactions with other parents met through the epilepsy foundation of South Africa (SANEL http://www.epilepsy.org.za/index1.html) over several years and limited Literature that I had access to.

³ Throughout this dissertation special educational needs will be referred to as SEN

1.2 Organization of the chapters

Robson states that "there is little consensus on the format for reporting qualitative research" and that "case studies can be written up in many different ways" (2002:507,511). However, Robson is in agreement with Bell regarding the importance of producing a well structured, logical and clearly coherent body of work where "the criteria will depend on the nature of the research" (1999:210,211) the intended audience and/or institution's requirements. Therefore in the attempt to provide this organizational clarity of format a brief overview of the chapters will follow.

Chapter one provides an insight into what this research entails. A brief introductory outline is followed by a more in depth discussion of context and significance of the research. A listing of the research questions are included in this initial chapter, clearly setting the research criteria and highlighting the areas of focus. The medical components of an LGS diagnosis have far reaching effects and are seen to be pervasive throughout the research. Therefore the section clarifying medically related components in this initial chapter are invaluable for providing a source to reference to throughout the proceeding chapters and discussion. Chapter two explores the methodology used throughout the research for both data collection and analysis. Aspects of rationale, methodological challenges and ethical considerations are included. In chapter three, the literature review is undertaken. As a possible starting point a brief methodological description is added as a form of guidance for future researchers. Relevant literature is reviewed and discussed with attention given to obtain as wide an understanding as possible of what has been accomplished to date by preceding researchers relevant to LGS in this field or other. Chapter four introduces Peter⁴ the subject of this case study. All aspects related to Peter, his educational experiences and surroundings are discussed within a given contextual framework. Due to limitations in word count for this dissertation 'snapshots' of different lessons throughout the days observed are taken and discussed in more detail while maintaining the focus on their impact related to the educational experience of the child.

⁴ Actual name was replaced with a pseudonym for protection of child's privacy and ethical responsibility of researcher towards respecting all participants rights.

From this discussion some recommendations are raised and elaborated on in Chapter five. Chapter six provides a platform for possible future research and discussion relevant to the inclusion process of all children with special education needs including LGS. A comprehensive list of references used is provided in Chapter seven and Chapter eight lists some useful bibliographic sources for additional reading and providing of a well rounded approach to this subject. In this chapter several informative web sites are given, some with personal accounts by parents of children with LGS being discussed. A thorough representation of data as a means of clarification and supporting evidence is provided as Appendices (1-14) in Chapter nine, concluding this research dissertation.

1.3 Background

This research was centred around a case study based on the daily reality experienced by a thirteen year old expatriate (male) child with a medically diagnosed condition known as Lennox Gastaut Syndrome (LGS). LGS being a diagnosis of a childhood epilepsy syndrome (Besag 2004:S5-6) which is by nature very unstable in how it manifests on a daily basis per individual.(i.e. The amount of seizure activity being experienced at any given time and associated interacting factors such as high medication levels) ⁵. This is discussed in more detail under medical background experiences of the research was on the holistic SEN and education related experiences of this representative child with LGS. The study was located and conducted within a private specialized therapy centre in Dubai, the United Arab Emirates (UAE).

The UAE is a fairly young country having been founded in 1971 and consists of the seven former Trucial states now Emirates of Abu Dhabi, Dubai, Sharjah, Ajman, Umm al Qaiwan, Fujairah and Ras al Khaimah, all previously 'governed' by Britain (Heard-Bey 2004:367). The UAE is situated along the Arabian Gulf between the Sultanate of Oman to the East and Saudi Arabia to the West (Bradshaw et al. 2004:49; Heard-Bey 2004:i,7) (Appendix 10: a and b). Bradshaw et al. continues "that there are no political parties or

⁵ Please see Chapter 9 Appendix 9 for a list of common characteristics associated with LGS as related to Peter

⁶ Please see Chapter 1 section 1.3 Background, subsection 1.3.1 Medical Background pg 14

elections" (2004:50) as the individual Emirates are ruled by Sheikdoms or monarchies which are federated (Burden- Leahy 2005:130) to form a central government of the UAE.

The local Emirati component of the population is small at "about twenty percent" (Shaw et al. 1995:8) with a strong local culture where fundamentals of the Islamic faith "dominates the cultural, moral, social, economic, legal and political" aspects of life (Heard-Bey 2004:135). The remaining population consists of a large expatriate community of varied nationalities (Gaad 2001:195; Whetter 2000: 161) which is "constantly fluctuating" (Heard-Bey 2004: xxiii) due to the transient nature of the contract based employment practiced here (7). As a result there are a large number of private schools in the UAE with considerable differences in curricula being offered in order to cater for the diversity in "religious, cultural and education needs" of these varied expatriate groups (Bradshaw et al. 2004:50) while the government schools serve the local Arabic population. In the latter "public education at all levels is provided free of charge" (Bahgat 1999:130) while "schools are gender segregated" (Shaw et al. 1995:8) from the third grade.

This duality in education provision is mirrored in regard to SEN where it is offered in the form of a few government run "Centres for preparation and Rehabilitation for the Handicapped" (Gaad 2001:196). The latter rehabilitation/therapy specialized centres are exclusively for locals while various specialized private therapy centres are open to all nationalities. Notably all SEN centres are situated outside of mainstream schooling (Gaad 2001:195). Gaad continues that centres for specialized education fall under the authority of the Ministry of Labour and Social Affairs instead of the Education Ministry (2001:202). Legally in the UAE primary education is compulsory however currently "there is no federal legislation requiring accessibility for people with special needs" (Bradshaw et al. 2004:51). In government and private schools children with highly visible or profound special educational needs are not enrolled but are referred to centres for specialized education (private or government) or kept at home (Bradshaw et al. 2004:52). In cases where the disability is less obvious the child may be enrolled in a private school

⁷ http://www.7days.ae/lifestyle/why-every-child-deserves-a-chance.html

by default or 'allowed' to stay in a special education class within a government school. This is achieved through repeated grade retention until the third grade after which the child is either able to resume mainstream classes or asked to leave and move to specialized education at a private or government centre. (Bradshaw et al. 2004:52, 3)

1.3.1 Researcher's Background

As a researcher I have worked both formally (teaching) and informally (assisting or volunteering) with children having SEN, including multiple disabilities for several years in South Africa and for the past two years in Dubai. My reflections related to LGS are based on my insider knowledge of being a parent of a child experiencing LGS⁸ and from experiences gained through my involvement with and teaching of children diagnosed with LGS and/or from information obtained through interactions with affected families met through the epilepsy foundation of South Africa (SANEL http://www.epilepsy.org.za/index1.html) over several years.

1.3.2 Medical Background

The identification of LGS is solely medically based therefore for the purpose of clarity related to this research a summary of terminology and related factors outlining this diagnosis are given and briefly discussed. LGS is defined as the medical term used to define an intractable epileptic syndrome (Camfield and Camfield 2002:31; Ogawa et al. 2001:197) where epilepsy is defined as an individual having recurrent seizures (Walker and Shorovon 1999:18), while syndrome, refers to a "set of physical conditions" as related to a specific medical problem (Hornby 2000:1216), or as "clusters of symptoms that tend to occur together" (Cardwell et al. 2004:727). Although this epileptic syndrome is rare where "annual incidence of LGS in children is approximately 2 per 100,000 children" (10), representing about 5% of children with childhood epilepsy (Wheless and

⁸ Please see Chapter 2 section 2.2 Methodological challenges pg 24 for a discussion of possible issues regarding bias etc

⁹ A sudden attack which effects the brain , a disruption in normal brain function

¹⁰ http://www.emedicine.com/neuro/topic186.htm

Constantinou 1997:203), its refractory nature ensures that it achieves greater exposure. This syndrome is named after the two Doctors, Dr. William Lennox and Dr. Henri Gastaut (Wheless and Constantinou 1997:203), who independently made significant contributions (11) resulting in, defining, by categorizing and diagnosis, of this Epileptic Syndrome.

Once a LGS diagnosis is suspected the most common means of identification is determined by a Neurologist through the use of an electroencephalogram (EEG) which measures brain wave activity of the child (Walker and Shorovon 1999:26,27) where LGS is categorized by an "abnormal" EEG with a particular pattern of "diffuse, slow spikewave discharges" (Besag 2004:S5). Further characteristic of LGS is the presence of frequently occurring and several varied seizure types (Freeman et al.1997:61-69,115) with Atonic¹², Tonic¹³, atypical absence¹⁴ and Tonic-clonic¹⁵ being the most common (Freeman et al.1997:61-69,115) but not restricted to these. LGS is also associated with Status Epilepticus¹⁶ which can be convulsive¹⁷ or non convulsive¹⁸ (Freeman et al.1997:151- 156). Regardless of which ever seizures are manifest they are further categorized as being resistant 19 to drug therapy and require polypharmacy 20 which will make seizure control very difficult to achieve or sustain for any length of time (De los Reves et al. 2004:254). Further more lowered intellectual and impaired cognitive functioning (21) is always associated with and evident in LGS, in varied degrees per individual case, either evident prior to onset or seen to become apparent and develop within the gradual development of LGS (²²) and accumulative (Besag 2004: S6-S7; Freeman et al. 1997:115; Ogawa et al. 2001:197, 201). This is either as a direct result of

¹¹ http://neurologia.rediris.es/congresco-1/conferencias/epilepsia-8.html

¹² A sudden loss of muscle tone resulting in falling and serious injury, drop attacks

¹³ A sudden rigidity of muscle tone resulting in falling and possible injury

¹⁴ A period of altered consciousness but no loss in overall body tone

¹⁵ Generalized convulsive seizure most commonly known or associated as being epileptic

¹⁶ A seizure which lasts for a very long time and can be life threatening, seen as a medical emergency

¹⁷ Person is seen to be 'shaking' having a tonic clonic seizure (see footnote 15)

¹⁸ Person appears confused, unresponsive or very response delayed while conscious

¹⁹ Difficult to control with medication, with many medications losing effectiveness over time

²⁰ Numerous medications used in conjunction

http://www.epilepsynse.org.uk/pages/whatsnew/review/spring04 2.cfm http://www.emedicine.com/neuro/topic186.htm

the underlying cause of the condition where a brain trauma²³ of some sort has occurred, the toxicity and sedative effects of the anticonvulscent drugs, the disruptive nature of the seizures to normal daily functioning and/or the continual 'electrical abnormalities' experienced in the brain. (Freeman et al. 1997:115) (²⁴).

Despite these commonalities variability does occur with individual patients exhibiting characteristics of LGS in varying forms and severity "as with most diagnosis in medicine, there is a range of outcomes" (Freeman et al.1997: 116). Benbadis states that "unlike a disease, syndrome does not have a single known aetiology²⁵ or pathology" (²⁶). One third of LGS cases are cryptogenic²⁷ (²⁸).

Average intelligence quotient (IQ) score is significantly lower in patients with symptomatic²⁹ LGS than in those with cryptogenic LGS, which includes patients for whom no cause of LGS can be identified but a cause is suspected. (³⁰)

(Freeman et al. 1997:115)

Early identification and intervention is hampered due to onset of LGS often not being apparent at birth (Camfield and Camfield 2002:31) with the average age for development of this syndrome being age three (³¹). However it can occur typically anywhere between the ages of one and eight with pre school children³² showing more prevalence, (³³) and a slightly higher occurrence among boys than girls (³⁴).

²³ Causes, if possible to determine, can include head injury, degenerative diseases, etc. (Freeman et al.1997:115)

²⁴ http://www.specialchild.com/archives/dz-017.html

²⁵ Scientific study of causes

²⁶ http://www.findarticles.com/p/articles/mi_m3225/is_1_64/ai_76414077/print

Without a known cause

²⁸ http://www.specialchild.com/archives/dz-017.html

²⁹ Symptoms or signs of a known cause

³⁰ http://www.emedicine.com/neuro/topic186.htm

³¹ http://www.specialchild.com/archives/dz-017.html

 $[\]frac{32}{\text{Mean age}} = 3$

³³ http://www.epilepsynse.org.uk/pages/whatsnew/review/spring04 2.cfm

http://www.emedicine.com/neuro/topic186.htm

Another important intrinsic quality of LGS is the resultant existence and accumulative development of complex medical and other disabilities including 'Autistic like' characteristics (Boyer et al.1981 cited Besag 2004:S5) for the child with certain typical features and similarities (Given as a range of common characteristics in Appendix 9) occurring in each case. Many of the characteristics are medication related (Wallace 1995:218)(35) but due to the nature of LGS as stated above numerous other factors may be interrelated or also be the cause requiring more thorough investigation on a case by case approach. This will enable a more holistic view being obtained of the effect of LGS on the general health of the child despite the pessimistic future predicted in majority of cases (Besag 2004:S6).

1.4 Research Questions

In this research the following questions will be raised and attempted to answer namely:

- What is life at school like for a child with Lennox Gastaut Syndrome?
- What is defined as education for a child with LGS?
- How can education be made accessible to a child with LGS?
- What possible recommendations can be made to aid educational provision for children with LGS in the classroom?

In order to explore what school life is like for this child with LGS I will be looking at educational provision within the UAE which will also include related social aspects such as teachers, attitudes, stigma etc.

1.5 Significance of this Research

"Epilepsy is one of the most common chronic medical disorders of childhood" and yet "there have been relatively few population based studies in childhood and most of these

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³⁵ http://www.emedicine.com/neuro/topic186.htm

have given little information about seizure types and especially about epilepsy syndromes" (Tidman et al. 2003:47). Additionally Besag (2004:S3) argues that aspects of behaviour associated with this syndrome has not received adequate research attention, "despite the fact that behaviour may have a profound affect on relationships, education, and the options for vocational training or employment." Absence of this research has an effect on education as indicated by Scrambler's statement that unfortunately many educators, school related administrators and school health personnel "still view epilepsy as a simple construct of major and minor seizures, with very little knowledge about its many different forms, both clinical and sub-clinical, which may be constraining the growth of learning and behaviour in children" (1990 cited in Johnson and Thomas 1999:18). This is despite the fact that epilepsy and Lennox Gastaut Syndrome are medical diagnoses that directly impact on education where "children with severe epilepsy often have associated learning difficulties" (Tidman et al. 2003:47). Due to the high focus on seizures, finding placement is problematic as schools (definitely) and centres (occasionally) may be reluctant to assume responsibility for even the relatively short school day. Therefore the result for many children with LGS is denial of the opportunity and right to being educated due to fears surrounding their seizures and related medical issues (Gibson and Blandford 2005:6). This is perpetuated by the continued use of medical models as the only means of diagnosis associated with LGS where the associated pessimistic medical prognosis forms the only reference point currently portrayed in literature (Besag 2004: S7). Williams and Heslop further support and sum up that "a medical model tends to prioritise the illness rather than the person behind the label; and particular diagnoses may lead to experiences of stigma and discrimination" (2005:232). The significance of this research lies in the unique (research) opportunity to contribute to the literature by providing an insight into alternative aspects of LGS (other than medical) with the focus on education thereby 'demystify the medical myth' where it is portrayed and assumed that only 'professionals' are capable of providing for the needs of children within this category (Cornwall and Robertson 1999:8).

Therefore although LGS is a rare syndrome, (Camfield and Camfield 2002:31) it could be viewed as representative of numerous other rare and/or medical conditions where

globally there is a call for inclusion and yet due to lack of alternative information (research), medical models and subsequent labelling (Williams and Heslop 2005:232) still prevail as a means to exclude many SEN children from education. This is summed up by Petty as "Each learner is unique and has individual needs. If the needs of our learners are discovered and met, the chances of success (referring to educating) are greatly increased" (2004:496). Cooper extends this thought when he comments that a current view expressed by "psychologists and educationists" is that "effective teaching always involves creating circumstances that cater for the characteristics of individual children" (1999:25).

2. Chapter 2 - Methodology and Data Collection

2. Chapter 2 - Methodology and Data Collection

Facts do not cease to exist because they are ignored.

(Aldous Huxley cited in Collins 2003:161)

2.1 Methods and rationale

Mertens defines the purpose of qualitative methods in research as providing "an in-depth description of a specific program, practice or setting" (1998:159). In the process of education and educating, diverse and complex activities and/or interactions occur within a classroom resulting in a lot of observable activity at any given moment (Wragg 1999:2, 5) which becomes a source of considerable collectable data (Cohen et al. (2000:147). Mertens supports this sentiment stating "that a considerable amount of work occurs during the data collection and analysis phases of a qualitative study" (1998:348, 9). Additional to this there are the complexities and intricacies of individual children to be considered. In this particular research a further consideration is the presence of a Special education need in the form of a medical diagnosis of LGS, which can vary greatly in its symptomatic manifestations³⁶. As a result in reality its range of complex issues which can consist of many diverse possibilities may be discounted or go unnoticed in less detail orientated data collection methods. Therefore choice of methodology for this research was based on Qualitative methods which are by nature more descriptive of finer details in the reality of everyday occurrences than Quantitative data would be (Robson 2002:455). Within this framework and as this is a unique case a case study approach was chosen as it is best suited for collecting detailed data about an individual in their particular setting or context where case study is defined as "a strategy for exploring the complexity, embedded character and specificity of a real life phenomena" (Gillham 2000 cited Porter and Lacey 2005:105). Bassey describes a case study as an "examination of an instance in action" which is "conducted in depth in natural settings" (1999:24, 47). Schostak supports this sentiment with his statement that "qualitative research seeks its data from the way in which realities are framed and potentially reframed" (2002:101). This raises

³⁶ Please see Chapter 1 subsection 1.3.1 Medical background pg 14 and Appendix 9 for further clarifications and information

one of several points of contention and criticism regarding the sole use of qualitative methods including case study (Bassey 1999:34-5) for data collection in research which I have been made aware of through the literature (Robson 2002:43,168; Cohen et al. 2000: 26, 7; Porter and Lacey 2005: 104,105) and although I have strived to be sensitive to the issues raised further discussion falls beyond the scope and restraints of this dissertation. Therefore in support of the methods chosen and used for this research, I offer Cohen et al.'s argument that defines the merit and worth of using case studies where:

Unlike the experimenter who manipulates variables to determine their causal significance or the surveyor who asks standardized questions of large, representative samples of individuals, the case study researcher typically observes the characteristics of an individual unit — a child, a clique, a school or a community. The purpose of such observation is to probe deeply and to analyse intensively the multifarious phenomena that constitute the life cycle of the unit with a view to establish generalizations about the wider population to which that unit belongs.

(2000:185)

Furthermore for the purpose of validity extensive data triangulation (Robson 2002:174, 5; Rudestam and Newton 2001:100) was used during the data collection and analysis phases of this research where varied sources were used in collecting of data related to this case study. These consisted of data collected from two full school day classroom observations spaced over two weeks, a semi-structured interview based questionnaire, discussions with relevant teachers and therapists as well as evaluative and supporting documentation related to the child's learning in the classroom. The latter consisted of any substantiating or related reports from other sources, professional or other, class work, Independent education plans (IEP) etc, and is included in the appendices (Chapter 9).

Observations were on a non-participant basis (Appendices 1 and 2) in agreement with Silverman (2003:233-248) who argues in favour of being non responsive in the classroom

and thereby avoiding influencing as far as possible of the observation through direct interaction, while still acquiring descriptive data of actual occurrences and behaviour (Robson 2002:310- 312). Robson continues that "to be highly involved risks compromising our researcher role" (2002: 311).

In an effort to control reliability of data collected, data was corroborated via cross referencing where possible (Robson 2002:101) with information collected from other sources. Further more interviews conducted individually with the class teacher, speech therapist and occupational therapist (Appendix 5: 1-17 a, b and c) were based on semi structured questionnaires in accordance with Silverman's discussion that the use of same format and sequence when applied to words and questions for each participant is one way of controlling for reliability (1993 cited in Cohen et al. 2000:121). During the design and implementation of the questionnaire cognisance was taken of Scheurich's (1995 cited in Cohen et al. 2000:121) point that controlling of the wording does not necessarily result in control of the data received due to the inherent open-ended nature of social interaction. To avoid possible influence of the observation process all interviews were only conducted after completion of all observations had been concluded.

After each period of observation and interview a clear written account of the data observed was compared to the audio recorded file for clarity and accuracy of content before the latter was labelled and digitally stored³⁷. Relevant anecdotal information observed or obtained informally is referred to as part of informal interviews with the participants and date given where possible.

³⁷ A summarized account of each observation and structured interview can be found in the Appendices 1, 2 and 5.

2.2 Methodological challenges

Prosperity is a great teacher; adversity a greater.

(William Hazlitt cited in Collins 2003:10)

In this section issues, limitations and/or barriers related to possible bias, ethics and ethical considerations relevant to this research will be discussed. As these will contain overlapping areas they are discussed under a single heading.

Prior to data collection permission was sought and obtained from the participants and assurances given that anonymity would be given while protection of personal privacy would be respected and strived for. In this regard actual names have been altered and pseudonyms used with specific locations not included (Robson 2002:501-2). In order to respect participants rights and maintain ethical standards every effort was made to adhere to all other ethical considerations (Mertens and McLaughlin 2004:151). The findings were presented in a final report with optional access for comment made available to all participants.

I faced several ethical issues within this research. First and foremost there is the issue of potential bias and conflicting roles on my part as a researcher, teacher, parent and observer. This is related to accuracy and objectivity and raises the question, in what part will I be reflecting as the researcher due to the numerous possible roles I find myself in? (Walford 2001:79). A child with LGS is labelled by default through medical diagnosis (Ho 2004:89) and a "diagnosis of epilepsy" still "carries with it an associated social stigma" (MacLeod and Austin 2003:112) therefore it is understandable that dealing with your child being identified and or labelled with the relevant perceived negative connotations is still a sensitive issue for many parents as can be seen in Faber and Mazlish (1995:249). As I am aware of my possible bias as a parent of a child with LGS, which could even unintentionally affect the collecting and processing of data, interviews with the parents were not included in this study other than including background information regarding Peter's current health status and past educational factual history.

However on a positive note I was able to utilize my 'insider' view of being a parent of a child with LGS to reflect on and evaluate the literature and current case study with a high level of motivation and understanding of the subject which could only come from having lived in a similar situation. Geeter et al. acknowledge the important role that parents fill in this regard as well as the information they could contribute to "determining the child's needs" and "planning of the required care and education" (2002:443). Russell is in agreement and further discusses the merits of parents in partnership with or in the role of the researcher (2004:74).

A further issue raised through the literature was by Cohen et al. in regard to editing, where identification of significant features (for future focus) was the primary objective for filtering of the data. However, he continues that through this narrowing down of the data via selection of significance, attention needs to be paid to the 'halo effect' (2000:157). This can be clarified as information already know or recently acquired regarding the context of the study and or participants, possibly being used to influence selection of data collection. Having been made aware of this issue through the literature I limited obtaining further knowledge from interviews etc prior to the observations other than identification of the child being observed and verification of a LGS diagnosis. Further means to regarding objectivity, reduction of possible bias and therefore validity of data are discussed in the methods previously.³⁸

A limitation faced was in regard to the limited available literature related to LGS which is predominantly of a complex technical medical nature. As I am personally lacking in a professional medically related qualification, processing of the data proved time consuming and problematic at times to determine its value and relevance for including or excluding in this study. Also in this regard the ethical consideration of which if any professional assessment reports to include was considered. Therefore in agreement with Mertens and McLaughlin's statement that "researchers should only attempt to undertake research in areas in which they are competent to do so" focus was kept on education and medical information only provided as background (2004:152). Similarly the validity and

³⁸ Please see Chapter 2 Methodology and Data Collection section 2.1 Methods and rationale pg 21

appropriateness of which educational assessment tests such as Intelligence Quotient (IQ) tests etc, can be administered is already strongly debated in literature (Howe 1990; Nettlebeck 1990 cited in Cooper 1999:87). This would prove even more challenging with LGS which is by nature very unstable in how it manifests on a daily basis per individual (i.e. The amount of seizure activity being experienced at any given time and associated interacting factors such as high medication levels). Even in a non medical assessment of children with LGS controversy would be based on how well the chosen test could be said to "measure an underlying theoretical construct" (Cooper 1999:86) in a situation that is not stable and ranges in expression on a daily basis while accumulative and continual(³⁹) cognitive damage occurs.

Therefore as assessment is used to create a benchmark of the child's abilities and limitations as well as subsequent needs in order to establish alternatives through which education can be accessed (Cornwall and Robertson 1999:20) I did not feel it was ethically responsible on my part to include Peter's psychological reports and comments related to his IQ in this study as once officially documented they could possibly be misconstrued.⁴⁰

Another point of concern was related to the consistency of the observed data collected where access was the limiting factor as it is not possible to predict in advance how many days or even full days the child with LGS will be able to be present at school based on health. Therefore I was obliged to schedule observations over a short interval of time whereas data collected over an extended period in a possible new future or follow up study may prove more representative of Peter's educational experiences. Unfortunately the latter did not fall within the scope of this study.

I was aware of the sensitivity of all the current issues or topics of importance to the subject namely special education needs and epilepsy in broad terms within the local context of an external society created framework of culture, ethics and legislation in the

http://www.specialchild.com/archives/dz-017.html
 Please see Chapter 4 section 4.1 Case background pg 38 for a reference to previous testing of Peter's IQ

UAE. Currently in the rapidly developing UAE (Gaad 2004:322), education and inclusion related issues and boundaries such as accessibility and rights of all children to be educated are reported on and evident in the local media on an almost daily basis (41); (42). However the labelling of children with special needs and the associated social stigma which also extends to their teachers by default (Gaad 2004: 623,4) is still locally prevalent and further compounded by the terminology used to discuss special needs.

⁴¹ http://www.7days.ae/lifestyle/why-every-child-deserves-a-chance.html http://213.132.44.184/emiratestoday/

3. Chapter 3 - Literature Review

3. Chapter 3 - Literature Review

The greatest part of a writer's time is spent in reading, in order to write: a man will turn over half a library to make one book.

(Samuel Johnson cited in Collins 2003:382)

3.1 Introduction

The primary purpose of this literature review was aimed at establishing the extent or absence of research which has been undertaken regarding LGS where the focus was not solely on medical or related aspects.

3.2 Methods used in the Literature Review

Access to various databases was enabled via the British University in Dubai (BUiD), in association with the University of Birmingham's devolved Athens authentication. Three major databases were searched online in order to identify research related to LGS, epilepsy and related education focused topics, including special education needs. These were IngentaConnect, ScienceDirect and Swetswise. Only journals with full text access were selected. The subject field was initially restricted to Education but was wavered in order to widen the search. Year of publication was extended to include sources older than five years as initial searches did not provide many articles. Key words used included Lennox Gastaut Syndrome, Epilepsy, Epileptic syndromes, Childhood epilepsies, Behaviour, Education, Special Education Needs, teachers, Multiple and profound special needs, United Arab Emirates as well as variations and combinations of all of the above mentioned. Additionally several web sites were identified and listed in the references (Chapter 7) and/or bibliography (Chapter 8) at the end of this dissertation as sources of informative and supportive literature. They are not reviewed as their content is subject to change due to the fluid nature of internet based sources.

3.3 Discussion of the Literature Reviewed

In reading this literature review the reader may feel the style is like a story telling. However as I had to obtain references to LGS with the focus on education and related aspects in such a myriad of often indirect sources, I found this style the most conducive in producing a coherent view of the 'available' literature. I begin this chapter with my conclusion that based on a review of the literature this condition appears to be under researched regarding any aspects which are not medical in nature (Besag 2004:S3, S5; Camfield and Camfield 2002:31; Freeman et al. 1997:116; Tidman et al. 2003:47; Kramer et al. 1998:49; Wheless and Constantinou 1997:203). Literature or lack thereof, which led to this conclusion, is now discussed.

During an initial library and other ⁴³ based search various books were considered and discarded as being too 'medical' or technical in content while only repeating the knowledge already available from the articles searched. An exception was *Seizure and Epilepsy in Childhood A Guide for Parents* by Freeman et al. (1997), were although this book is fairly old I found it invaluable as a comprehensive lay person's guide to all the complexities, definitions, treatments, side effects of medications and related aspects associated with childhood epilepsy, in particular the information regarding syndromes including comprehensive references to LGS. There is also a brief discussion regarding aspects of education with a holistic view on the life of a child with epilepsy being offered. There were very few articles with LGS in the title therefore older and/or related articles that had been manually checked for relevance and previous research done were also included.

Using the methods described and within the limitations set by the criteria and focus of this study several searches resulted in only one primary article being found with LGS as the title and sole focus, namely by Wheless and Constantinou. (1997:203-211) This

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⁴³ This refers to the physical library on British University of Dubai's campus as well as searches at the sole local academic textbook stockist and other book stores in the Emirates. The first mentioned does not provide for detailed medical reference books as this is not a focus area of study currently offered at this institution while the latter only provided technical medical tomes.

article provides a thorough overview of the syndrome including expected prognosis, historical background, diagnosis and evaluation as well as possible treatment options. As the authors are both medical doctors the article is fairly technical in style with medical aspects the focus however there are a few concluding lines related to quality of life and impact on families. This style and content was repeated in the majority of secondary articles and sources found and reviewed where LGS was a part of the title but not the main focus (De los Reyes et al. 2004; Hosain et al. 2003; Huber et al. 2003; Kaminska et al. 1999 and Ogawa 2001) or was only included as a small subsection of the larger discussion in the article (Besag 2004; Camfield and Camfield 2002 and Wallace 1995). In continuing the medical theme of research evident with LGS in the literature many of these articles were focused on the effects both positive and negative with subsequent evaluations of "the newer AEDS (antiepileptic drugs or medications), approved in the 1990's" which had been developed in order to "offer new options for the treatment of individuals with developmental disability and epilepsy" (Rutecki and Gidal 2002:S24). Due to the "progressive intellectual decline in LGS" being "related to seizure burden and cognitive side effects of medication used to treat" it (Hosain et al.2003:16) there is a consensus amongst the articles reviewed that this line of research be supported and expanded on as "the newer AEDs have some beneficial effects" (Wallace 1995:219). Rutecki and Gidal further support and justify this aspect of research related to LGS as a means to improve quality of life through the "attempt to obtain better control (of seizures) with newer AEDs" (2002:S30). Huber extols "the development of each new AED (as) a glimmer of hope" for those people with "high seizure frequency, multiple seizure types, frequent complications, such as status epilepticus or injuries, and a high rate of therapy resistance" all of which categorizes LGS (2004:168). However Huber continues by cautioning that "further study is needed to clarify" AEDs and their impact on refractory epilepsies like LGS (2004:175). Hosain et al. expands on this call asserting that "continued research toward better understanding of this syndrome should be a priority (2003:19) thereby indicating the need for future research not to be limited to medical only issues but to include all aspects of LGS in order to ensure a more holistic view. "Little is written about the social consequences of LGS; however, our clinical experience suggests that they are profound" (Camfield and Camfield 2002: 31).

In order to further explore these claims and statements a broader search of epilepsy was undertaken which resulted in issues of related behaviour being found to have become a focus of recent research (Austin et al. 2004; Besag 2003; Boel 2004; Caplan et al. 2005; Datta et al. 2005; Masia and Devinsky 2000). On closer examination of these articles it was found that although aspects of behaviour related to epilepsy were researched the focus was greatly varied and of questionable value regarding the holistic quality of life reality of the (individual) children in the studies. Also lacking was provision of adequate information in order to produce viable recommendations for improvement of the latter. Although Austin et al. have focused on parental and/or family influences and impact regarding behaviour associated with severe epilepsy, they have also clearly acknowledged the need for "early and follow-up assessment of child behaviour problems" with emphasis on "development interventions and programs" for future reference (2004:S40). Of concern is perpetuation of the medical model by Austin et al. in stating the need to including "mental health professionals to assess and treat behaviour problems found in children with seizures" (2004:S40). The article by Besag provides the sole direct reference to education and LGS where he expresses surprise at the lack of documented research regarding "the behavioural aspects of these syndromes, despite the fact that behaviour may have a profound affect on relationships, **education**, and the options for vocational training or employment" (2004:S3). Besag then continues by indicated the need for "good research" directly linked to LGS and other epileptic syndromes despite the "complexity of the behavioural problems that may be associated" with this diagnosis which can "arise from a combination of factors" (2004:S7). Many of the articles still retain a strong medical or technical style as indicated by Boel's discussion regarding possible profiling of behaviour linked to specific epilepsy category (2004:291-297). This was also the case with the article by Griffith et al. which highlighted depression as a common behaviour associated with individuals with "treatment resistant seizures" (2005:1). Having made me aware of this possibility to take into account during my research I was ethically 44 unable to comment further on the merits of these studies due to lack of a personal professional medical or psychological qualification from which to draw in-depth conclusions from. However, Griffith et al.

⁴⁴ Please see Chapter 2 Methodology and Data collection, section 2.2 Methodological challenges pg 24

states, that the "clinical significance" of the "scores⁴⁵ among seizure disorder patients is not clear" and that their results are suggestive of being effective as indicators of depressive symptoms within this population category (2005:1). Boel sets a limitation of his study as "the fact that a variety of factors influence learning and behaviour" including aspects of the environment along with the medical components (2004:295). This supports my approach in proposing research around the holistic educational environment and experience of the child with LGS.

Therefore in order to explore the holistic setting and environmental context of this case study, published literature regarding the UAE was included in the literature review. The latter was found to be sparse when linked to education or special education needs. A sentiment supported by Shaw et al. as "a pressing need for research in management and development" of schools in the area (1995:8). As "the education system of the UAE, in comparison to other countries is relatively new 46, this could be considered to be one reason for the limited availability and variety regarding educational research literature currently experienced (Gaad et al. 2006: forthcoming). A discussion by Bahgat of the differences, albeit historical at times, in the education systems of the region including the UAE places it in context to its Gulf neighbours and enables clearer understanding of the region's workings which may otherwise appear very alien to a western audience (1999: 127-136). Bradshaw et al. continue with a more up to date discussion of the implementation of the education system in the UAE (2004: 49-55). Of particular interest is their focus on special education needs and introduction of ongoing research related to teacher's attitudes towards inclusive practices being introduced in the UAE in the future (Bradshaw 2003 cited in Bradshaw et al. 2004:54). Gaad continues this focus within the UAE through an article examining the attitudes of pre-service teachers in guiding their choice of career in SEN (2004: 619-631) and another on educating of children with Down's syndrome (2001:195-203). The importance of prevailing "social influence" (Gaad 2004:622,624,629) regarding SEN within the context of the local culture, is highlighted and discussed (Gaad 2001:195). Each culture gives rise to particular

⁴⁵ Obtained from use of the Profile of Mood States (POMS) Depression (D) scale to indicate a depressed mood in patients with seizure disorders. (Griffith et al. 2005:1)

⁴⁶ Please see Chapter 1 Introduction, section 1.3 Background pg12

prevailing attitudes and beliefs originating from the "customs and social behaviour" of that particular society (Soanes and Stevenson 2003:422). In a further article Gaad argues that these culturally specific "attitudes drive our behaviour" (2004:313) in providing a corresponding moral or ethical framework of what would be considered acceptable or unacceptable behaviour. This in turn affects the way in which individuals and their needs are constructed and will be treated or provided for accordingly (Gaad 2004:624).

The topic of labelling or stigmatizing is also raised. This is relevant to my research as "throughout history, people with epilepsy have suffered from a social disease as much as from a neurologic disorder" (Masia and Devinsky 2000:34). Alghazo and Gaad further discuss teachers and "their acceptance of the inclusion of students with disabilities" within a UAE context (2004:94). In general their study results indicated that most teachers were not in favour and that further training and 'education' of the latter was required if changes were to be possible in the future. The strong influence of cultural beliefs and constructs within this society was again found to underpin this outcome. As the literature has indicated the strong influence cultural beliefs can have on education for a child with SEN including epilepsy, further review of the subject was undertaken with stigma and labelling as the focus. From the literature there is consensus that stigma features prominently linked to a diagnosis of epilepsy (MacLeod and Austin 2003; Lee et al. 2005; Fernandes et al. 2005; Masia and Devinsky 2000) and impacts negatively on the individual's quality of life. Less clear were the exact effects and causes (Lee et al. 2005:157) as these can vary in degree of severity as well as how it is experienced exactly (MacLeod and Austin 2003:116). The issues of labels and labelling are more complex although no less contentious (Ho 2004; Corbett 1996). There is considerable discussion about the purpose of labelling. Is it a means to obtain information via associated prognosis and securing of benefits and facilities or a means to perpetuate medical models and school exclusion? (Freeman 1997:224).

This led to an evaluation of literature regarding schools as they are considered as the "second most important social environment for the child after family" (Prpic et al. 2003:142). From the selection of literature (Wodrich et al. 2006; Johnson and Thomas

1999) available, teacher's role and attitudes (Prpic et al. 2003; Bishop and Slevin 2004) related to students with epilepsy in school was again frequently found be a focus point.

No research regarding education and special education needs would be complete without including a brief discussion on inclusion. However as much as already been written and published in the literature about this subject I refrained from officially including and reviewing the subject yet again within this review although this study does contain several references to it.

From the literature reviewed and interpretation of results from the various previous studies undertaken a summary indicating the gaps in research could be developed. This led to the constructing of a conceptual framework where the need for further research regarding LGS and new research on an education focus related to it is the resultant conclusion.

4. Chapter 4 – Case Study findings: Peter's school day.

4. Chapter 4 – Case Study findings: Peter's school day.

From each according to his abilities, to each according to his needs.

(Karl Marx cited in Collins 2003:1)

Every effort was be made to view and represent this proposed case study from as many perspectives as possible in order to gain a thorough view of all aspects related and possible factors which may have an effect on the situation. This included the internal learning environment, including aspects such as the curriculum, other students or peers, teachers and therapists as well as the external environment reflective of the public views and influences etc. (Ware 2003:1-4)

4.1 Case Background: Meet Peter

'Peter', ⁴⁷ an expatriate 13 year old boy is the subject of this case study research. He is experiencing exceptional learning difficulties and subsequent educational needs directly related to his diagnosis ⁴⁸ which is categorized as a childhood epilepsy syndrome: Lennox Gastaut Syndrome (Besag 2004:S5-6). ⁴⁹ To date no known cause for Peter's LGS diagnosis has been identifiable ⁵⁰(⁵¹) since its initial manifestation just prior to age three. Peter receives all medication at home consisting of five different types, 18 tablets daily. ⁵² His parents (informal interview December 2005) currently view his seizures as relatively 'controlled' in that he only experiences predominantly absence seizures. For the past two years since September 2004 Peter has been enrolled at a private specialized therapy centre 'school' for special needs education in Dubai, United Arab Emirates (UAE). Previous to this Peter's school experience has been limited to three brief trial periods at

⁴⁷ All names used are fictitious to protect the privacy of participants.

⁴⁸ Identification is solely medically based and diagnosed by a Neurologist with an EEG test or Electroencephalogram – A medical test to measure brain wave activity and the main test used to verify a Lennox Gastaut Syndrome diagnosis.

⁴⁹ Please see Chapter 1 Introduction, section 1.3.1 Medical background pg 14 for additional information and clarifications.

⁵⁰ One third of LGS cases are cryptogenic or without a known cause.

⁵¹ http://www.specialchild.com/archives/dz-017.html

⁵² Nitrazepam, Sodium Valproate, Topiramate, Clonazepam and Lamotrigine

specialized schools (Appendix 7) in his home country supplemented by various modified home schooling programmes (Informal interview with parents 19/12/05). According to his parents, these trial periods were considered to be relatively unsuccessful as the resources and education being offered was not suited to meet Peter's needs at the time. His parents state that indication of Peter's IQ is unknown as previous tests by a clinical psychologist proved inconclusive due to large variations and extremes in test scores; however he is categorized as having loss of cognitive function.⁵³

4.2 Structure of Peter's School Day.

4.2.1 Observational Context

Mixed Nationalities and disabilities are catered for in the private centre in which I have conducted my research. Due to the children all having varied diagnosis and wide variability in their skills and abilities separate grades are not used to group children but rather ranges of similar age are implemented. Separation of gender only occurs in the two senior classes (age range 12-18) as a reflective responsive to the local culture (Gaad 2006: forthcoming) despite the international composition of the centre including staff (administrative and teaching etc.) and pupils. Consequently Peter is in all boys' class of eleven children with ages ranging from 12 to 18. In his class lessons are predominantly in English with Arabic translation being used for the children that don't have a clear understanding and/or have Arabic as their first language.

4.2.2 Classroom Organization

There are always two teachers present and at times a volunteer. The class room layout⁵⁴ is informal in that the children sit in a single group with the desks joined in a rectangle so they face each other. The class is divided for academic skill development activities such

⁵³ Psychological report not included for ethical reasons and protection of Peter and his family's privacy. For other aspects related to this omission please see chapter 2 section 2.2 Methodological challenges page 24

The Learning environment discussed is referenced to in Appendix 1: 1-3 and appendices 3 and 4.

as literacy or numeracy etc, into two groups of 5 and 6, based on student ability. When splitting into the two smaller groups the same seating on a smaller scale is repeated. All other activities are done as a single group. On occasion Peter's group will split further into another two groups of two and four where Peter and another student are paired together while the remaining four students of the group working together (Appendix 1:3).

There are many issues related to grouping some of which Lewis (1995:106 - 123) discusses however further discussion falls outside the parameters of this study. Lessons are varied according to a structured timetable for each day (Appendix 12). A large visual timetable in the form of stickers is seen on the whiteboard along with a marked calendar relevant to the day observed. The classroom appeared well resourced with educational supplies and the walls of the classroom were bright and colourful with educational aids and/or examples of student's work. A copy of Peter's work/ behaviour contract with his teacher (Appendix 14) was seen on the wall next to the whiteboard. All lessons are conducted by the class teachers within the classroom with a few notable exceptions such as music, physical education (sports) and individual therapy sessions. According to their specific schedule individual children leave the classroom during the week to attend 'one to one' speech therapy sessions in a separate classroom (Appendix 11: a) while music or library lessons take place in the appropriately equipped areas of the centre. Physical education activities vary between swimming, time spent using gym equipment or sport activities in the sports hall or outside play area. All three of these activities have their own designated Teachers. An occupational Therapist conducts a lesson with the students as a group on a weekly basis in their classroom (Appendix 2: 42- 96 and Appendix 11: b).

Peter's classroom is located at the back of the school and consists of a large central room and small bathroom. There is an additional kitchen type washbasin, refrigerator, several cupboards, large bookcases, a couch, a carpet, a shelving unit for school bags/ lunch bags (Appendix 2:38) and a computer in the room along with shelves for resources, props etc. The layout of the desks are described in Appendix 1:1-3 and presented diagrammatically in Appendices 3 and 4. There are two small windows in the top half of the double door entrance and a row of windows runs down two sides of the classroom near the very high

ceilings. Due to the high placement of the latter (i.e. well above eye level) distraction is eliminated while natural light is not sacrificed. Ambient light and temperature were observed to be adequate. Noise experienced within the classroom depended on activity of the lesson. His learning environment can be considered to be well organized and comfortable to promote and facilitate learning while reducing distractions.

4.2.3 Observations and Discussion

Appendix 12– Fixed Weekly timetable of scheduled class activities per day.

	RASHID	PAEDIATR	TIMIETABLE	CENTRE	
Time	SATURDAY	SUNDAY	MONDAY	TUESDAY	WEDNESDAY
8:00- 08:30	Teacher's time	Teacher's time	Teacher's time	Teacher's time	Teacher's time
08:30- 09:00	CALENDER	CALENDER	CALENDER	CALENDER	CALENDER
09:00- 09:30	ACADEMIC	CARPENTARY	MUSIC THERAPY	GYM	ACADEMIC
09:30- 10:00	ACADEMIC	CARPENTARY	ACADEMIC	PLANTING	ACADEMIC
10:00- 10:30	ART	CARPENTARY	ACADEMIC	PLANTING	COOKING
10:30- 11:00	SNACK	SNACK	SNACK	SNACK	COOKING
11:00- 11:30	RELIGION	ACADEMIC	DAILY LIFE SKILLS	SHOPPING	SEWING
11:30- 12:00	RELIGION	MUSIC	SWIMMIMG	SHOPPING	SEWING
12:00- 12:30	OCCUPATIONAL	GYM	SWIMMING	SHOPPING	MUSIC
12:30- 01:00	OCCUPATIONAL	GYM	SWIMMING	SHOPPING FEEDBACK	FINE MOTOF SKILLS

Peter was observed formally and informally within the classroom on several occasions, he is familiar with the observer and therefore all observations had an interactive component. The school week consisting of 5 days runs from Saturday till Wednesday, starting at 8:30 and ending at 13:00. Saturday is the first day of the school week and Wednesday the last. There is no communal recess. Excerpts are taken from the highlighted lessons in the time table as given above (and/or in Appendix 12) and discussed below.

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⁵⁵ Every attempt was made to avoid bias and contamination of observations by only including characteristics that were corroborated by a second source other than the observer, such as the teacher etc.

Peter is described as experiencing numerous learning difficulties and therefore has special educational needs according to his teacher, occupational therapist and speech therapist. These are particularly apparent when he is tired or stressed (Appendix 1: 97, 137) but not limited to it. This point the class teacher responded strongly about, as she mentioned it more than once, (Appendix 5:5a, 8a, 9a) namely that Peter's emotional state at a given time greatly affected his ability to learn and be taught. "He gets stuck when not happy. He can't focus, can't do work. Happy and healthy is important!" (Appendix 5:9a).

4.2.3.1 Life Skills - Cooking Lesson

This observation took place in the classroom during the mid morning cookery based life skills lesson, approximately for one hour from 10:00 to 11:00 on a Wednesday which is the last day of the school week (Appendix 1: 75- 117) concluding with a trip to the bathroom (Appendix 1:115) and subsequent snack time for the children. The latter coincides with the end of the cooking lesson as the cooked product is the snack in this case. On any other day the children bring a snack from home (Appendix 2:38) and/or money to buy 'tuck' (Appendix 1:112). The Children eat at their desks.

Peter's teacher is aware (Appendices 8,9, 11c and 14) that he is easily distracted and has a short attention span coupled with confusion and resistance to change when 'sudden' new situations which he has not been prepared for become necessary or arise as in the case for subsequent lesson changes throughout the day (Appendix 1: 117, 118). Therefore during the preceding academic lesson she starts preparing Peter for the cookery lesson by introducing him to what is to follow, "Today we have cooking" and gives him an indication of what they will be cooking with prompts like the question "Who likes pizza?" (Appendix 1: 13). The latter is also the teacher's way of trying to ensure that she gains his interest and attention as well as enough time to prepare him for the cooking lesson scheduled to follow. When this does not appear to be working (as he is still looking else where) the teacher is seen to use a combined auditory and visual approach as a second prompt and reinforcement of the subject of pizza, redirecting Peter by name to a large brightly coloured card with the word 'pizza' on it while emphasising its starting

letter sound (Appendix 1:14). This has the desired effect as Peter acknowledges the card by holding it and indicates eating associated with it when he holds it to his mouth (Appendix 1:14). The teacher doesn't push the point further at this stage, "I will be back now" (Appendix 1:14). When she is no longer providing Peter with one to one attention, he is seen to become unfocused and distracted (Appendix 1: 15, 17, 26). However after a period of time he becomes aware of and increasingly preoccupied with the card the teacher has given him, constantly handling and fidgeting with it. He appears aware that he should be doing something with the card but is not entirely sure what it is or what the word on the card is anymore. He has either forgotten or can't recall it from memory and becomes agitated and unable to sit still (Appendix 1:18). Peter is seen to be resourceful, trying to obtain help from his peers when he can't figure it out himself.

Peter is now looking back at the card and wiggling his hands. He is sitting down again and mumbling to himself with a frown on his face while playing with the card. Peter asks student C⁵⁶ in a quiet voice, "C, what's this word?" Peter holds the word up in front of C in imitation of what the teacher was doing previously. Peter is quiet now and checking to see what the teacher and other group are doing. Peter touches his mouth again etc.

(Appendix 1:17)

When the teacher returns she reintroduces the cooking concept by repeating the card naming process, "What is this?" (Appendix 1:18). She then continues by reinforcing the word through association to concepts of eating. With this additional sound and action, "Mmmmmmm....." while indicating licking her lips and rubbing her stomach (Appendix 1:18), the teacher is providing Peter with a practical and visual reminder to enable him to remember and recall the word 'pizza' with for future use. Peter's preference and enthusiasm for learning via games is evident (Appendix 1:20) in the change in his demeanour where he is observed to smile broadly (Appendix 1:19), giggle (Appendix 1:23) and even laugh out loud (Appendix 1:22) more frequently during game

⁵⁶ Letter of the alphabet chosen at random to indicate a fellow student (Appendices 1,2)

activities. The teacher supports this observation, "He learns with play, practical examples are very important" (Appendix 5:4a). Most of the learning style employed by the class teacher relied on interaction. This was largely created through the use of repeated questions (Appendix 1:13, 14, 18, 22, 27), discussion (Appendix 1:33, 68-70) and activity such as games with props (Appendix 1:22, 23). In continuing the speech therapist lists "making things fun to learn, with visual props" (Appendix 5:12c) as part of Peter's learning style. Vail states "since people are multi faceted, each person has more than one way of learning. But most of us have predominant clusters, preferred channels" (1992) cited in Ginnis 2002:37). Therefore the importance of determining Peter's preferred learning style and incorporating elements of it to aid successful learning can be summed up as a means to develop learning strategies which will have a greater probability of successfully reaching him (Ginnis 2002:172). Rettig supports this view and further explores and describes the eight different learning styles or multiple intelligences as originally theorized by Gardiner (2005: 25-256). In continuing Rettig adds that "educating children with disabilities through the multiple intelligences may help us to discover or 'awaken' hidden talents" as well as helping them to "discover what they are good at and put a focus on ability rather than disability" (2005:256) thereby moving away from a medical model type categorizing of the child (Gibson and Blandford 2005: 6). In this regard Peter's teacher categorizes him as a predominantly kinaesthetic styled learner (Appendix 5:12a). This finding is supported by his previous school (Appendix 7). Petty describes this learning style as a preference to "learn new ideas by handling real objects and by making and doing something; to learn by stimulation, work experience, and by doing something in the real world" (2004:146). This increased and focused participating from Peter is utilized and capitalised on by the teacher when she introduces food props in a guessing type game (Appendix 1:21-29) a little later.

The teacher places her hand on Peter's shoulder and says "Head up close eyes." Peter puts his hands out in front of him without prompts indicating he is familiar with the pattern of this activity. The teacher puts a tomato in his hands. Peter laughs out loud. Teacher asks "What is this?" Peter is smiling and holding the tomato with both hands, eyes

still held tightly shut. The teacher prompts "Touch it with your hands." The teacher helps Peter to reform his hands over the tomato. Peter rubs one hand over the top. Peter smiles and says "Its an apple." He appears to be enjoying the 'game' as he is paying full attention and still keeping his eyes tightly squeezed together. The teacher replies with a question "Is it...?" Peter is smiling and giggling. He repeats softly "apple.....?" The teacher continues "No........ you can slice it, put it in a salad........what is it?" Peter shouts out excitedly "Maatoe." The teacher says "excellent!" Peter opens his eyes and looks at the tomato in his hands.

(Appendix 1: 22-24)

Further observations of Peter's reliance on physical activity as a preferred means to learn is seen on several occasions throughout the lesson where he often indicates by mimicking physically what he wants to do or what another student has to do in the activity or task (Appendix 1:32, 75, 81, 93).

When the Teacher is speaking to another student, encouraging them to cut Peter softly says "I'd like to cut" while moving his hands over each other in a backwards forwards cutting motion. Peter sits leaning forward in his chair, he wants to cut, moving his one hand indicating cutting of the mushroom he is still holding in the container while watching every movement of the student's hands who is busy cutting.

(Appendix 1:81)

Peter had problems paying attention for any length of time unless really interested in the activity (Appendix 1: 62,65,67,109,110) or being kept on task through one to one attention from his teacher (Appendix 1: 66,69). The teacher is aware of Peter's need for constant guidance, "he needs me one to one a lot" (Appendix 5:11a). She lists it as a concern and stress on her teaching and classroom management when describing

implications of having Peter in her classroom. Without the latter or when the teacher is distracted (Appendix 1: 89, 90) he is seen to frequently lose focus (Appendix 1:86, 97,102,115) and/or start to fidget (Appendix 1:19, 75,107). This loss of focus is seen when he is observed "staring at his pizza and eating one piece of sausage after another without even looking at the bowl of sausage pieces he is eating from" (Appendix 1:95). The occupational therapist also recognizes Peter's need for individualized attention due to his "inability to remain engaged" therefore requiring "specific attention to maintain him within his work" (Appendix 5: 4b).

As described by Maranzo et al. (2001:132) the teacher used a varied approach to teaching with repetition for reinforcing. This is seen when to further prepare Peter for the cooking lesson to follow, the concept is again introduced and reinforced by the teacher when she lets Peter prepare some of the ingredients in advance (Appendix 1:61-67). The teacher employs peer tutoring here as a means to provide additional 'one on one' focused help, notably with Peter being encouraged to help his fellow student and show him how to wash vegetables (Appendix 1: 61,62).

It is generally acknowledged that peers act as influential models for each other, and that peer acceptance and approval can be powerful incentives.

(Beveridge 1999:93)

The influence of peers in the classroom and learning process is also evident where Peter was often seen to be watching the other children for visual clues during activities that required interaction (Appendix 1: 66, 68, 93, 102). "He keeps glancing at the other students to see what they are doing, following their activities with his eyes" (Appendix 1:67). The teacher, occupational and speech therapists are in agreement that Peter has good verbal skills and is socially communicative (Appendix 5:8a,b and c). Peter was observed to initiate conversation and to verbally engage his peers socially (Appendix 1: 88, 107). Although he usually gets a favourable reciprocal response, Peter only spontaneously engages peers and/or adults on an individual basis and never instigates interaction towards a larger group. The occupational therapist views Peter's social ability

as a strength in the context where it enables her as a fairly new addition (Appendix 5:3b) to his educational team to still be able to build up a mutual rapport favourable to providing therapy.

He is social, not afraid. Its not hard to build up rapport some children won't work with new therapists but he doesn't mind new people like that.

(Appendix 5:5b)

The last part of this statement indicates that Peter accepts new people in his school life provided its within his 'comfort zone' or familiar territory. (i.e. his classroom) The speech therapist continues on this theme indicating that "he needs to practice social skills in group situations and manage unfamiliar situations independently" (Appendix 5:6c).

To keep his attention and focus on the task at hand the teacher has to frequently redirect him to the activity by either calling him by name and/or verbally repeating instructions several times. As well as with physical prompting (Appendix 1:29, 85) and reminding him to make eye contact, "last one open your eyes open your ears and look at me" (Appendix 1:39).

Peter is observed reacting strongly to sensory input related to temperature.

The Teacher continues to hand out the dough bases and confirms the children's reaction with "Yes its cold. Dough was in the freezer." Peter won't hold the base with his hands. He has it on a plate and touches it with just his finger tips.

(Appendix 1:91)

Peter is helping the teacher to take the cooked pizzas off the baking tray using his hands as instructed:

He exclaims "Yeow!" followed by shaking his hand and blowing on it. The teacher checks the pizza, it is warm but not hot. She says "Not hot.. not hot at all..... use your hands." He does gingerly with just his fingertips.

(Appendix 1:109)

This is one of a common range of characteristics associated with LGS listed as a "Heightened sensitivity of the skin to hot/cold (exaggerated response)" (Appendix 9).

Poor impulse control (Camfield and Camfield 2002:31) where Peter can't seem to wait for his turn during activities is an issue listed according to his IEP (Appendix 8: d and e) which requires focus in order to improve. Evidence of the latter was seen when Peter constantly interrupts or shouts out throughout the lesson (Appendix 1: 8, 9, 42, 71, 82,) or is reluctant to give his fellow students their turn (Appendix 1: 110, 111) which results in the teacher having to reprimand him on more than one occasion and remind him to give others a turn (Appendix 1: 86).

Evidence of seizure activity is difficult to verify in the classroom. Peter's sudden mood changes including starting to cry (Appendix 1:86), sudden onset lethargy seen in lowered levels of physical interaction (Appendix 1:97) and episodes of unresponsiveness where his "face is without expression and appears slack or unfocused" (Appendix 1:86), may be indications but this is not conclusive evidence. Another example is when both his class teacher and the Arabic teacher aren't able to engage him get a response out of him despite their combined efforts,

Teacher 2 (the Arabic teacher) asks him "Why you don't want this ...?"

Teacher 2 points at the green peppers and when Peter doesn't respond he says "Capsicums?" Peter appears confused or non responsive, makes no reply, mouth slack, staring in front of him at the capsicum plate. Teacher says "Peter don't ignore me (no reponse or movement from Peter) look at me" Still nothing from Peter.

(Appendix 1:95, 96)

It is here where it can be seen that the presence and manifestation of several seizure types (Freeman et al.1997:61-69,115) are a major challenge for the teacher as some of the latter such as absence seizures or non convulsive status epilepticus⁵⁷ are impossible to detect without medical testing as the child in this state is conscious but not very responsive (Camfield and Camfield 2002:31). Therefore the teacher may not know whether or not Peter's behaviour is due to acting out or in response to what is happening in the class because he may not be cognitively present and fully aware of his surroundings or what is being taught at all times. Conversely Peter's hand tremor is physically apparent and fluctuates in intensity (Appendix 1: 70, 84) depending on his energy level and activity being pursued.

"Peter is shaking more noticeably now with the effort to slice but continues."

(Appendix 1: 77)

It appears that this is not of great consequence or detriment to Peter's ability and functioning regarding this lesson other than providing him with some frustration when his hands can't match his expectations, causing him to knock off some previously carefully placed ingredients he had spent considerable time placing (Appendix 1: 99- 101). However following a discussion with the teacher (informal interview 18/12/05) and on being shown samples of Peter's poor writing skills (Appendix 11: a, c) the impact of his tremor on his weak fine motor skills can be clearly seen. The latter is a focus area for development towards his annual goals for the year, as reflected in his IEP (Appendix 8: b).

Another very challenging aspect of educating Peter according to his teacher (Appendix 5:9a) and speech therapist (Appendix 5:11c) refers to Peter frequently 'getting stuck' where he appears unable to move on to another activity (Appendix 1:92, 101).

Peter says "I know how to cut mushroom." He sees more mushrooms in a Packet and is fixated on them. He asks Teacher 2 (T2: the Arabic teacher),

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⁵⁷ Please see Chapter 1 section 1.3 Background sub section 1.3.1 Medical background pg 14 for clarification of seizure types etc.

"I'll I'll pass mushrooms to you?" P is 'stuck' on the mushrooms and cutting them. He points at the cut pieces and directs (T2) "You can take this." T2 is busy with multi tasking between the students and tells Peter to wait. Peter is not paying attention he is cutting and cutting more and more mushrooms. The class teacher notices and says "Enough. Enough (She takes the knife) my dear." Peter looks up in a daze to see where the knife went, sees the teacher lifting his board and says "I'll do it", followed by him emptying the board.

(Appendix 1:88-90).

Similarly he appears to get stuck when he is unable to remain focused on what he was going to say and 'forgets' his train of thought and so keeps repeating his starting phrase.

He asks "Can I? Can I?" pauses then repeats.

(Peter appears stuck) The T says "Can I what?" but gets no response.

(Appendix 1: 104).

His speech therapist refers to this type of perseverance (Appendix 9) behaviour as Peter appearing to be unwilling at times to stop the activity he is currently engaged in. She elaborates,

He is very set in his ways, you have to find a way around because he gets stuck, or wants the same etc. We were working with a card game 'people who help us'. From the beginning he wanted the music band card he had remembered from before. Then when we get to, now all mix them up (the cards), no. He wants music band so no cooperation, do I push it or go round? To reach my goal for him I go around.

(Appendix 5:9c, 4c)

This behaviour has been targeted in his class IEP where the teacher has written "Peter will use many colours with his colouring, not just green" (Appendix 8: c).

4.2.3.2 Academic Skills – Money concepts

This observed 'money concepts' lesson took place in the classroom after the music lesson on a Wednesday (Appendix 1:118- 130). It is classified as a fine motor skills development lesson due to the small props used and took place over approximately half an hour from 12:30 to 13:00 (Appendix 12). This was the last activity of the day before the students left to go home for the weekend.

Peter's preference for learning via games is utilized once more and extended to include role play when the teacher introduces 'playing shop keeper' (Appendix 1:120) and reversal of roles (Appendix 1: 122) during this lesson. The use of role play and its effectiveness as a learning tool is well documented in literature (Ginnis 2002:49; Lee et al. 2001:66; Petty 2004 245-8). Gross sees the use of role play as twofold in "providing work which will translate abstract into concrete" while providing a "supportive structure, or scaffolding, which can slowly be withdrawn" as the child becomes "more familiar with the process of turning problems into operations" (2002:216). "It is this supported involvement which helps to develop fully fledged ideas and concepts and to build independent skills and competencies" (Babbage et al. 1999:80). In this regard the use of role play could be said to be particularly suited to this lesson where mathematical concepts which are abstract in nature are being taught in a way Peter will be able to relate to (for example when he goes 'shopping' with his class for ingredients they will be using during their cooking lesson Appendix 1: 71; Appendix 5: 6c; Appendix 12) and conceptualize in a practical format. The latter refers to developing of skills which will enable him to discriminate between the cost of items (Appendix 1: 120,129) and enable him to practice budgeting through simple addition and subtraction when given a choice in what he wants to buy versus how much money he has available(Appendix 1: 121,126,128,130).

There was brief evidence of rote learning (Petty 2004: 11, 13) where,

both Peter and C count out the plastic coins one at a time

while placing them into the teacher's hands, 1, ... 2,... 3, ... 4, ... 5. A short pause to pick up more coins and then Counting resumes 6-10. (Appendix 1:119).

The brief middle pause and rhythmic counting observed indicative of a learnt sequence pattern. However the teacher did make considerable efforts to incorporate this means of 'surface learning' to the 'understanding' component of what was being taught, namely number understanding related to money concepts. The teacher supports my observed view and qualifies her choice of methods stating,

He needs academic skills but functional e.g. when teaching money concept, generate it to practical examples like props and the Mall when we go shopping etc. You need to 'brainstorm' with him to bring the topic back and refocus him.

(Appendix 5: 6c)

Peter's poor impulsive verbal control when it comes to interrupting and resistance to 'turn taking' is again noted during this lesson (Appendix 1: 122, 125). He is aware that this is a problem and shows a willingness to correct it as he asks the teacher on one occasion if the other student he is paired with, C, should have a turn when they are asked to open some boxes in preparing for the lesson (Appendix 1:119). This occurred during a less excitable time in the lesson which may indicate that his subsequent frequent interruptions are related to times when Peter's heightened excitement levels levelled at the activity at hand are the cause of his behaviour due to his distraction and lessened awareness of control at these times.

The delivery of this lesson although in appearances based purely on a game was very focused on meeting and developing his cognitive skills as stipulated in Peter's current IEP, with accurate targeting of listed goals (Appendix 8: c). The use of the relatively small coin props (Appendix 1:119) also ensure Peter's fine motor skills which he has a problem with due to his hand tremor (Appendix 9) are developed.

Of interest was the identified unique to the 'Middle East' part of the role play, namely bargaining or haggling over price. A social and culturally based aspect particularly relevant to this region is the 'skill' of bargaining (Whetter 2000:191) which Peter will have been exposed to in his outings to the shops with his class or parents. Due to Peter's verbal (Appendix 5:5a; Appendix 1: 99,117) and sociable nature (Appendix 5:8a,b and c) the incorporation of bargaining in the money concepts lesson role played was exceptionally well received by him which bodes well for his learning as his "good days are the best days for teaching" according to his teacher (Appendix 5:9a). However tongue in cheek, I should add it is less sure whether the class helper would 'appreciate' Peter's already strong verbal sparring abilities (Appendix 1:117) developed and honed further when he is already capable of providing a strong argument.

The teacher tells Peter "I want to buy some stuff from you...." Now in this role play she will be the customer and Peter the shop keeper. He is sitting calmly in his chair without fidgeting and is smiling, he arranges the food items and is keen to begin. The teacher points at the first item and asks "How much is this juice?" Peter is very confident in his role as the shopkeeper and immediately says "3 Dirham⁵⁸!" The teacher acts shocked holding her hand to her mouth and exclaims "Very expensive! This juice is 2 Dirham outside. (Meaning at the shops outside this 'school' shop)" More play acting from the teacher who puts her hands on her hips and then wags her finger at him saying "You are cheating me its very costly." The teacher and Peter bargain back and forth in a big game that both appear familiar with because Peter says "Ok you know I'll give you a better price." The teacher laughs and says "I will only give you 2 (Dirham), you want it or not?" Peter is nodding and laughing so much he can hardly take the coins. He starts to count 1, ... 2 and takes 2 coins from her hands. The teacher claps her hands together and tells him she is very pleased that

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⁵⁸ The name of the local UAE currency unit (Whetter 2000:156).

(Appendix 1: 122-124)

Peter also relies on this strength in verbal ability observed in his constant stream of self dialogue where he instructs and reminds himself what to do or steps to take in activities (Appendix 1:99).

Despite Peter being categorized as having loss of cognitive function and his current level of cognitive functioning being unknown⁵⁹ at this time, he is clearly aware of what constitutes reality versus make believe in this instance and is able to discriminate as seen when he refers to his tuck money as "Look I'll show you real money" (Appendix 1:125).

4.2.3.3 Occupational Therapy

This observation took place in the classroom on a Saturday, the first day of a new school week, consisting of the final hour of the day from 12:00 to 13:00 (Appendix 2:42-96). Directly after this lesson all the students went home either by bus or collected by their parents.

Initially the lesson starts off well with Peter extending his usual offer to help (Appendix 2:42). The occupational therapist indicates that this is typical behaviour for Peter as he is "friendly" and "always wants to help" (Appendix 5: 8b). This has been observed to be an accurate reflection as he is frequently heard extending an offer to help in previous lessons (Appendix 1:58, 64, 69, 77, 79, 82, 105 and Appendix 2: 72). The occupational therapist initiated the start of her lesson by recapping the work done in the previous lesson specifically singling Peter out to attempt ensuring she has obtained his attention. Petty relays the importance of summarizing and stressing "key points" when "beginning and at the end of classes" in order to deliver effective teaching (2004:16). Therefore theoretically this repetition of the previous lesson should have reassured Peter and acted

⁵⁹ Please see Chapter 4 section 4.1 Case background pg 38 for a reference to previous testing of Peter's IQ

as a means of reinforcement indicating what the therapist was intending for the lesson. In effect she was making "use of old learning in developing new learning" (Petty 2004:16). In practice this does not occur as Peter is experiencing extreme confusion and agitation (Appendix 2: 45-48, 53) when he is unable to accept that the 'car' he is given as his from the previous lesson is in fact his.

Peter is not happy with the car given to him and holds it up asking "Where is my car?" After no response he tries again "Green?" The Occupational Therapist doesn't look up she only replies "No, blue." Peter continues to shake his head and look at the other student's cars and the pile still being handed out. He is touching the other cars and turning them over appearing to be looking for something, maybe his name? The therapist finishes and notices Peter is trying to check cars by turning them over. She tells him "No", and gives him back his cardboard car. She continues "First one I threw because it was 'scrap'." Peter mumbles inaudibly before saying softly "OK." He sits down and runs his finger over the painted cardboard surface.

(Appendix 2: 45, 46)

However he clearly has not accepted this car as his own as he remains upset and after a brief period once again,

says loudly in a very upset voice, "Its not my car."
(Appendix 2: 48)

The use of the word 'green' (Appendix 2:45) also indicates that Peter is getting stuck on this concept as it is a noted colour he tends to fixate on according to his IEP (Appendix 8: c). This appears to set the tone for a large portion of the lesson and affects Peter's attention span and level of active participation. The impact and importance of Peter's environment and his level of comfort within it have already been discussed in the

previous lessons⁶⁰ (Appendix 5:5a, 8a, 9a). "Emotion is stronger than thinking" (Ginnis 2002:26). This is most noticeably seen in the change in Peter's demeanour and behaviour where he has been really upset about 'his car' when compared to the previous two lessons discussed.

In this regard Peter's physical appearance is notably altered which was not observed previously.

Peter has his head to one side and the irises of his eyes appear un-Centred and rolled upwards so that in appearance he appears unfocused and half asleep. He is constantly moving his eyes and blinking to refocus. His head is remaining at an angle towards his body. (Appendix 2:47)

To what extend this is due to his emotional state, increased seizure activity or other possible causes is unknown. The therapist is aware that Peter is "dependant and influenced by his environment" and states that she doesn't want to "stress him" however she feels he needs to be made to "stretch' a bit" (Appendix 5: 9b). The occupational therapist is sensitive to the fact that this may prove difficult (Appendix 5:2b). This is in agreement with his speech therapist's opinion that "keeping him focused and on task especially when he isn't having a good day" is one of the most challenging aspects of teaching and class management related to Peter (Appendix 5:9c). This mismatch in communication between Peter and his occupational therapist at this time may be due to the relatively short time they have worked together (Appendix 5:3b) not having allowed for a 'understanding' to be developed between them as yet. The class teacher describes a similar scenario when describing her initial interaction with Peter. She emphasises the need to "understand him" (Appendix 5:15a) in order to support his learning as well as Peter's need to have a "relationship with the person trying to teach him" (Appendix 5: 4a)

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⁶⁰ Please see Chapter 4 Case Study findings section 4.2 Structure of Peter's day subsection 4.2.3 Observations and Discussion etc pg 40

and not just relying on the fact that it is easy to "build rapport" (Appendix 5:5b) with him due to his "very social" temperament (Appendix 5: 8a, b, c and 10a).

In the beginning not now, I was shocked. We had a very big gap to understand each other.

(Appendix 5:15a)

Additionally another notable difference in this lesson was the expectation for Peter to work as part of the class or larger group (Appendix 5:3b) instead of his usual single peer pairing (Appendix 1: 3, 32,119). It should be noted that the children do not work as a group but predominantly independently while seated in a group as many primary school children are noted as doing by Galton et al. and Tizard et al. (1980, 1988 cited in Lewis 1995:115). There is also considerable less one to one help available to him in this situation. The result is that Peter is observed to lose concentration when trying to work independently "getting flustered and keeps restarting the count (of the car's plastic wheels)" as well as losing focus of his surroundings and activity of the lesson where frequently he is "looking very confused" (Appendix 2:52). The cumulative effect is that Peter is often observed withdrawing and becoming unresponsive (Appendix 2:52, 53, 55). The therapist's significant use of spoken Arabic (a language of which Peter has no understanding as he is a native English speaker) at this stage further exasperates his disengagement (Appendix 2: 53). It was not felt that this was intentional but rather an unconscious response to the predominate number of Arabic speakers in the class as the therapist has previously listed Peter's "inability to remain engaged" (Appendix 5: 4b) as one of his weaknesses.

Throughout the lesson the noise and activity levels due to student excitement and adult facilitated interaction is considerable (Appendix 2: 54, 57, 65, 66, 67, 76, 89). The prevailing sense of "ordered 'chaos' "(Appendix 2:66) in the classroom causes Peter to create his own 'space' where he is observed to "move(s) his car parts closer to his body with his arms and hold(s) on to the wheel and cardboard cut out" while "leaning over them with his body, with both his arms from the elbow to the hands flat and encircling

them on the table" (Appendix 2:54). This is Peter's coping mechanism for being in a bigger group as he "needs his own safe area, his own space when with the other children, else he gets jittery or gets preoccupied with them" (Appendix 5: 4b). Although Peter characteristically will keep trying and make attempts to master an activity (Appendix 5: 10 b) his increased frustration level in this lesson where he does not have as much one to one help is observed to directly corresponds to his visible hand tremor worsening and resulting in subsequent apathy (Appendix 2:58,59,63).

The situation improves once he is able to get this attention (Appendix 2: 72) and once a functional three dimensional shape is starting to form which requires more physical manipulation on his part and coincides with his preferred learning style⁶¹ (Appendix 2:61,70). Overall this lesson has focused on the development of Peter's fine motor skills, acquisition of patience and impulse control in waiting for turns as well as building tolerance of groups. In dealing with the latter light has been shed on Peter's self initiated creation of coping mechanisms which could be utilized further in making possible recommendations.

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⁶¹ Please see chapter 4 Case study findings, subsection 4.2.3.1 Life Skills - Cooking Lesson pg 41 for a discussion on Peter's preferred learning style.

5. Chapter 5 - Recommendations

5. Chapter 5 - Recommendations

What we have to learn to do, we learn by doing. (Aristotle 384- 322 BC cited in Collins 2003:240)

A recommendation is defined by Hornby as "the act of telling somebody that something is good or useful, the best thing to do" (2000:977). In this regard information from all the involved participants in Peter's education are taken into account when considering and stating possible recommendations. Peter's class teacher and therapists are in agreement that his environment has a considerable impact on his behaviour and learning (Appendix 5:4b; 5a; 8a; 9a, c). In discussing his temperament his class teacher states that he "is involved with his environment" indicating that she views Peter's environment as an intrinsic part of him (Appendix 5:8a). Due to all of these views it would be recommended and even necessitated that Peter's environment receives considerable more attention in order to fully understand its significance in his learning and ensure that its negative impact is minimized while its positive attributes are known and raised to facilitate his learning experience. Ware defines a "responsive environment" as one in "which people get responses to their actions, get the opportunity to give responses to the actions of others, and have the opportunity to take the lead in interaction" (2003:1). He argues that this type of environment benefits and even enables in some cases "social, communicative and intellectual development" (2003:1, 4).

While it is known that Peter benefits from and prefers one to one interactions (Appendices 5:7a, 8c, 11a, 12b, 16a and 7) it is not always practical to only work on an individual basis or feasible as indicated by the class teacher's 'stress' in noting that she isn't always spending enough time with the other children due to Peter's need for personal attention (Appendix 5:11a). Therefore the teacher felt that Peter would benefit from a "one to one shadow" teacher in the form of a full time teacher's assistant in the class to provide additional support and guidance for Peter while supporting him during activities (Appendix 5:16a). An added concern was that although his current placement in a class with a low teacher to pupil ratio (Gross and White 2003:81) ensures he receives

adequate supervision and Peter is mobile he isn't always very steady in his locomotion and coupled with a general disregard or unawareness of dangerous situations and impulsiveness (Appendix 9), could sustain considerable injury to himself or get lost by wandering off unattended. Therefore the further benefit of a full time assistant is argued for. While I am in agreement that he would benefit from the additional support as he "needs specific attention to maintain him within his work" (Appendix 5:4b), a negative result of full time help could be Peter losing his independence in class (Beveridge 1999: 96), all of which does not aid his inclusion and integration within his peer group as a whole. This would be a point of concern as Peter already has difficulties in group situations relating to his peers utilizing social communication and interaction (Appendix 2: 61, 85 and Appendix 5:4b). The introduction of games requiring group interaction and team building exercises would be beneficial in helping Peter to use his strong verbal and social skills with individuals to develop his weaker group communication skills (Appendix 5:6c), in effect using his strengths to build up a weakness. As suggested by the speech therapist (Appendix 5:15c), the introduction of a weekly news sharing time with the entire class where visual props have been used to provide support and structure to the delivery would be helpful in providing an opportunity for Peter to receive positive reinforcement in the form of interest and attention from his peers encouraging improved group cohesiveness.

The school does not have a social worker or counsellor on staff and no reference was made to aid Peter's social issues at this time regarding tolerating groups, group work and occasional inappropriate to age interaction (Appendix 2: 79, 83-85) with his peers, other than the support and guidance of the teacher within the classroom (Appendix 2:80, 81) and the speech therapist's during his one to one therapy sessions (Appendix 5: 7c, 17c). In Peter's therapy dialogue diary one entry from the latter states "First we had a little talk about Peter's worries" (Diary entry 21/11/05; informal interview with parents 18/12/05). Clearly in the case of the latter the impact of Peter's environment is once again seen to affect his education where he had to speak about his concerns before he could begin the lesson. These are the last few years for Peter and his class "as children with special needs before they become adults with special needs", requiring "skills to face the community,

leisure activities or productive work" (Appendix 5:15c). Therefore the introduction of a designated relevant professional therapist in the form of a counsellor, social worker or educational psychologist would be highly beneficial and recommended to minimize loss of valuable learning time. The latter would be achieved through the provision of aid with emotional issues and development of coping strategies, supportive guidance and tolerance counselling for dealing with this transition time, from teenager to young adult which is stressful for most children regardless of a presence of a SEN or not. It should also be noted that the timetable (Appendix 12) is not conducive to social interaction within the centre between the students of different classes as there is no communal recess etc. Social interaction is therefore limited to occasional mixing in the corridors or hall during sporadic school assembly type gatherings or in own class with peers. Therefore in order to encourage development of social skills across age and abilities it is recommended that a communal recess be implemented as soon as possible. Peter's consistent willingness to 'offer help' (Appendix 1:64, 79, 127 and Appendix 2:42) should be further harnessed and utilized to improve and develop "successful following through with instructions for simple tasks or errands when he isn't supported one to one" (Appendix 5: 6c). This would help Peter to become more independent and behave more age specific, "having things to do like (other) teenagers" (Appendix 5: 15c).

In regard to structure in lessons and activities, "Peter needs it to be very structured" (Appendix 5:15a) therefore the implementation of simple visual storyboards depicting a sequence of events or instructions for an activity would be greatly beneficial in providing an interesting and clear path for Peter to access should he become confused during the lesson or be unable to obtain one to one assistance for a brief time. Additionally these could be numbered. Instructions should be kept short and uncomplicated. The curriculum is already being differentiated to accommodate Peter (Appendix 5:14a,b,c) and I would recommend that this aspect be evaluated more fully to ensure that he is actually benefiting from how this is being decided and implemented .Wragg (1999:96) states

In any curriculum which is negotiated rather than imposed, both teacher and pupil may need to act more flexibly and responsibly to each other.

Flexibility is required in helping deliver diversity in lessons differentiated while striving to maintain a broad exposure to the curriculum for Peter in order to keep his interest and prevent boredom setting in (Appendix 5:6b). This is particularly relevant to LGS where although certain similarities in characteristics exist they can vary in their severity and so planning for alternatives would require a case by case approach. This is noted in Peter's IEP where his teacher states that his is very different from his peers while the rest of the students have similarities (Appendix 5: 11a). This necessitates time consuming modifications to curriculum to aid accessibility to learning as Peter has uneven skill development and education delivery should be focused at his strong verbal ability while working on his weak writing and reading separately⁶². Peter's problem with fine motor skills and hand tremor require additional time spent in the classroom on a one to one basis with the teacher or assistant in order to practice hand control for writing.

Peter responds well to assistive technology (AT) as seen by the 'certificate of achievement' he has been awarded for 'computer skills' from his previous school (Appendix 7) and yet no mention of this option has been made in his current IEP (Appendix 8). The presence of a single computer in the class (Appendices 3 and 4) could be problematic as he often gets 'stuck' and may not want to "move on" to do other less favoured activities as noted by his speech therapist (Appendix 5:9c). However provision of additional AT would be an effective enhancement to his education service and learning (Snowman and Biehler 2000:281-4) with lowered frustration levels and related mood swings. Ware discusses the role of using technology to enhance and aid delivery of the curriculum while maintaining a responsive environment further facilitated as "there is also now a huge range of IT ⁶³ equipment available from sophisticated multisensory environments (2003:105).

Gaining Peter's interest in an activity (Appendix 1: 32,48,62 etc) is observed to positively increase his cooperation, attention to task, focus and tolerance in how long he will be able to remain so and continue the learning process being offered. Therefore as

⁶² This is currently being worked on by Peter's teacher with the development of an individualized education plan (IEP) seen in Appendix 8. ⁶³ Information Technology

Peter is more visual and 'hands on' (Appendix 5:12b) in his learning and prefers practical kinaesthetic (physical) activity based lessons such as games using props (Appendix 1: 27, 28), puzzles (Appendices 2:5, 42 and 13) and practical /construction activities (Appendices 1:71 and 2: 61) his lessons should incorporate these as much as possible. However Petty states that although a student may have a preferred style of learning, this should not be used exclusively as "multiple representations of the concept" being taught would "allow them to experience it in different ways" which are all adding to the overall understanding (2004:140, 1).

This statement is based on his argument that "it used to be thought by some that learning styles were equivalent and interchangeable routes to the same destination and that students should use the road that suits them." Whereas "the emerging view is that each style offers a different perspective on the learning and that they are complementary and mutually supportive rather than interchangeable" (2004:151). He continues raising the possibility that this approach enables a student to work on areas of weakness while benefiting from stronger areas. As Peter has been identified as preferring kinaesthetic learning (Appendices 5:12a and 7) in accordance with further definition by Petty, a system allowing him to incorporate his need "to be able to move freely about the classroom and visit new places" (2004:146) should be introduced. If Peter could be allowed a 'safe' positive time out area equipped with manipulation props relevant to the lesson where he could move freely and interact with his environment and the support and direction of a one to one assistant, he may be better able to tolerate group work and maintain interest and focus on the lesson. In order to maintain order in the general class should this be implemented, the occupational therapist's recommended approach of providing "short, brief 'shots' intensive for any subject, delivered in structured brief time" should be implemented (Appendix 5:6b). The teacher is already providing a means for Peter to remain including within the class even when he is lethargic by having a couch present, on which he has taken several naps or 'rests'. "School for Peter stops at 12h:00. I can't push him more else he starts to cry. I can see he has had enough, sometimes he sleeps in the class (Appendix 1:137). Therefore this concept is not entirely new to his

education experience but could be developed further in order to be more productive as discussed in the above recommendations.

Currently most of Peter's logistical and some educational needs are being met in a specialized centre; however his areas of higher function are not being fully investigated or developed. During the lesson where a car was being made Peter spontaneously started to sing the end part of 'wheels on the bus....' (Appendix 2:86, 87) while working with the physical components notably wheels of his car in progress. Therefore Peter shows that he is capable at times of making independent connections between concepts in current lessons and associated activities previously learnt that are related. This indicates a need for further research in order to identify more fully his potential and to provide additional suitable recommendations. Expectations from all the recommendations would be to hopefully improve the level and completeness of the education Peter is able to receive through increasing his accessibility to the curriculum being provided.

Although Peter's present 'school' has medical staff present on the premises, as a final but vital recommendation their knowledge of LGS and that of his teachers should include **correct and current** knowledge of first aid related to seizures.

6. Chapter 6 – A Look into the Future

6. Chapter 6 – A Look into the Future

I don't understand why people are frightened of new ideas. I'm frightened of the old ones.

(Cage, J. 1912- 1992 cited in Collins 2003:216)

6.1 Discussion

Internationally there has been an increased awareness of children's rights, including the right of access to education (Daniels 2000:69,71; Engelbrecht et al.1999:47) with increased focus on the rights and needs being met of children with learning difficulties and/or disabilities(Thomas and Loxley 2001 cited in Brusling and Pepin 2003: 197). In regard to the latter the concept of inclusion arose, defined as:

a broad concept dealing with educational access, support for learning and 'equal opportunities for all pupils, whatever their age, gender, ethnicity, attainment and background'."

(OFSTED 2000 cited in Jones and Smith 2004:115)

Therefore although Inclusion may be a 'broad concept' with terminology in literature often used interchangeably with terms such as integration (Lomofsky and Lazarus 2001:306), it can be simplified in definition as the right of each child to accessible education at their neighbourhood school by being fully included regardless of their disabilities, abilities, race, gender, nationality or any other factor (Friend and Bursuck 2002:4; Mittler 2000: 10, 11). A further review of current literature clearly indicates that Inclusion and the call for inclusive schools has become a global phenomenon in education, both in terms of policy and delivery (Engelbrecht et al. 1999:24, 25; Mittler 2000:2, 13; Peters et al.2005:139; Gaad 2004:312; Frederickson et al. 2004:263; Heiman 2004:91). This is also currently reflected in the rapidly developing UAE (Gaad 2004:322), where education and inclusion related issues and boundaries are frequently

profiled in the local media⁶⁴. However Inclusion in the still fairly young and developing education system of the UAE has not been adopted in practice as yet. This is due to numerous reasons of which the most conspicuous is the fact that at the present time "there is no federal legislation requiring accessibility for people with special needs" to education in the UAE⁶⁵ (Bradshaw et al. 2004:51) and a society's culture and ethics reflective in its laws serve as a measure of how successfully the needs of its disabled members are met. Further in response to the latter the general population have as yet to adopt a "need for change" (Lieberman 1990 cited in Alghazo and Gaad 2004:98) outlook enabling changes to be made for all children with disabilities (including LGS) and their associated needs to be viewed as a higher priority than is currently the case, resulting in adequate measures being provided for and implemented.

Prpic et al. states that the importance of attending school is in the fact that "there with the acquisition of knowledge and skills, the child develops social skills as well (2003:142). In regard to Peter and possible inclusion his teacher and therapist were in agreement that he would benefit from being included into mainstream schooling (Appendix 5: 16a, b, c). However certain reservations were raised with indications that particular provisions would need to be provided for and implemented if this was to have a chance at being successful or even possible.

"One to one shadow. A very qualified general teacher" (Appendix 5: 16a).

"Needs to be done right. Everyone needs to be equipped and supported to get flexibility" (Appendix 5: 16b).

"Dependant on school and support, depends on country's system"

(Appendix 5: 16c).

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⁶⁴ Please see footnotes 41, 42 section 2.2 Methodological challenges pg 27

⁶⁵ As discussed in Chapter 1 section 1.3 Background pg 12

Francis and Muthukrishna (2004:116) state "On the positive side, inclusion can promote an awareness of difference and social exclusion" but note is also made to exercise caution in its implementation. For example in main stream schools were the teacher to student ratio (Schweisfurth 2002::41) is not usually as low as would be the case in a specialized centre the presence of a dedicated teacher's assistant and /or helper would be required to provide Peter with a high level of guided supervision in gaining academic skills and as a form of 'protection' to his surroundings while still allowing him to develop his independence (Lacey and Ouvry 1998:28).

Peter's occupational therapist adds that as there are "normal variances between all people in society, all will benefit from being in the same social group even if academic level is limited." She qualifies this belief with her opinion that "not everyone has a PhD but everyone has friends" (Appendix 5: 16b).

Peter's LGS characteristics directly impact his ability to learn (Camfield and Camfield 2002:32) (Appendices 1, 2, 5 and 9) and time that he is physically present in class. Therefore further research is essential to provide a better means of meeting his and other children's educational needs where LGS is the diagnosis. Creative management and planning of all educational resources and strategies will form an ongoing holistic student centred (Cornwall and Robertson 1999:56) approach to education possibilities. In order to determine and evaluate these future options regarding LGS, education and possible inclusion; the unknown will need to be discovered and uncovered. Currently what is known is that Lennox Gastaut Syndrome can be categorized as one of the "catastrophic epilepsies" (Camfield and Camfield 2002:30) or as a very complex medical condition which will impact heavily on all aspects of the individual's life. As a result of the magnitude of serious medical aspects related to it receiving most of the focus, very little attention is spared for other development of the child as a whole, integration into society (66) or development of a peer group (Chazan et al.1998: 127-129). Early intervention and corrective measures are imperative to limit 'damage' to the child as "a significant"

⁶⁶ http://www.epilepsynse.org.uk/pages/whatsnew/review/spring04 2.cfm

correlation exists between age of on set of seizures and mental deterioration" (⁶⁷). Information at this stage could also aid parents regarding possibilities for future education and enable them to make informed choices.

6.2 Personal Gains

As a researcher and parent of a child diagnosed with LGS, I have experienced the effect of LGS on a personal level and its implications regarding particularly lack of educational provision⁶⁸ and social isolation for the child therefore I am in agreement with Masia and Devinsky's statement that "Throughout history, people with epilepsy have suffered from a social disease as much as from a neurologic disorder" (2000:34). This along with the negative impact on the child and family (⁶⁹) could be considered to be one of the most serious implication aspects of LGS. Through the process of conducting this research a resultant reflection upon my past teaching methods occurred which has positively influenced my personal development as a teacher and will impact on future applications. My unique position due to the numerous roles I found myself in during this process⁷⁰, ongoing investigation of the literature and interactions with stakeholders in education have ensured a personal growth in understanding and gain in my knowledge of special educational needs, which I hope will be able to be expanded on in the future.

6.3 Conclusion

This study set out to examine the holistic education experience of a child with LGS and its implications. In this research all aspects of this child's school day were investigated and examined. Care was taken to include all participant's views and/or opinions. Supportive samples of class work were viewed and where possible their creation was documented. From the latter and comprehensive documented observations, possible recommendations were developed and discussed. Further the evidence gathered clearly

⁶⁷ http://www.emedicine.com/neuro/topic186.htm

A common opinion expressed by fellow parents as discussed, please see footnote 2 page 10 and Chapter 1 Introduction section 1.3 Background subsection 1.3.1 Researcher's Background pg 14

⁶⁹ http://www.epilepsynse.org.uk/pages/whatsnew/review/spring04 2.cfm

⁷⁰ Please see Chapter 2 Methodology and Data collection section 2.2 Methodological challenges pg 24

showed the influence and role of the teacher and therapists as educators in providing education for this child while highlighting aspects which are missing in a greater holistic approach. Therefore in concluding from all the evidence gathered I believe a child with LGS will benefit from being educated however it is only from further research that it will be determined what these benefits are and who are they for? The hope is therefore expressed that this research will lead to more research regarding other aspects of a child's life with LGS other than focusing predominantly on medical issues in isolation and be reflective of a more holistic approach. An overriding motivating factor being that without information the future outlook becomes impossible to prepare and plan for including education provision.

Education is simply the soul of a society as it passes

from one generation to another.

(The Observer 1924 cited in Collins 2003:133)

7. Chapter 7 - References

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9. Chapter 9 – Appendices

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9.1 Appendix 1 - summarized account of observation one.

9.1 Appendix 1 - summarized account of observation one.

Protocol 1

Researcher VJS

Date 14 December (Wednesday) 2005

Setting Specialized Centre/School in Dubai, U.A.E.

Senior Boys Classroom

Classroom age group range 12 - 18

Time 9h: 00 - 13h: 00

Lesson Varied activities across an entire school day

No. of students 11

Teachers 2 (1 male/ 1 female)

 $\begin{array}{ll} Classroom \ assistant & N/A \\ Therapist & N/A \end{array}$

Gender of class boys only

(When referring to other students in the class I have used letters of the alphabet chosen at random A, B, C etc and then consistently used as a means of identification to provide clarity in the transcript while maintaining protection of their privacy and anonyminity. Similarly adults present where identified according to assigned Code letters as given in the transcripts.) It should be noted that in the UAE the school week runs from Saturday to Wednesday, with Thursday and Friday as the weekend. This is in accordance with the Islamic faith and cultural practices of the country.

I am not introduced as I'm a non participant observer, however the children are familiar with me and my presence in the classroom as I have assisted the teacher as a volunteer on previous occasions therefore all observations had an interactive component. I sit towards the back of the classroom against the side wall for desk activity. On discussion with Peter's Teacher (T) it was decided that I would join the class for observation purposes after the children had been settled down by the morning routine (observed and documented at a later date) (Appendix 2:1).

⁷¹ Every attempt was made to avoid bias and contamination of observations by only including characteristics that were corroborated by a second source other than the observer, such as the teacher, speech therapist etc.

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- 2. There are two teachers in the classroom as the class gets split into an Arabic and English group for academic skills. (6 in the English group / female Teacher (T) and 5 in the Arabic group/ male Teacher (T2) (Please see 4.2.2 Classroom organization for a description of the classroom and learning environment layout and Appendices 3 and 4 for a diagrammatic representation).
- 3. The class now splits into the two groups for Academic skills. T asks the boys to move their desks. The students shift the desks from the single large group configuration (Appendix 3) to two smaller groups of 5 and 6 with the 'English' speaking group further dividing into another two separate groups of 2 and 4 (Appendix 4). The Arabic group has moved to the back of the classroom. There is a huge wooden bookcase which effectively divides the large classroom into two separately defined areas. Peter (P) is in the group of 2 and faces the other boy (C), sitting across from each other with desks end to end between them (Appendix 4).
- 4. The T gives the group of 4 boys work sheets and pencils, explains what has to be done. It is a repeated activity or one the students are familiar with, T says "ok, you know what to do boys." And then moves over to Peter and other student. Before T can start a student (B) from the other table asks "Is this mouse catching...?" T replies "I don't know I'm not with you...." The student then asks another student from the group of 4 softly "M is this.....?" T says "I'm listening......." T tells B "B listen. Is this.....?" T places stress on is this? And indicates to the paper.
- 5. T continues "This is a test for you to do by yourselves." The group of 4 start to concentrate (heads down) and work on the worksheet. T calls P by name. Gives student C across from him a ball. Puts laminated cards with words in front of them on desk. T ask C to find word for what he is holding. P paying attention to interaction. C indicates the correct word 'ball'. T says "very good. Ball." T points to the card and holds it up for C. He is very excited and noisy, chatting a lot. T says to both P and C "Shhhh, now listen."
- 6. T points to cards on desk, they are different colours with different words on them for the different toys the T has as visual props. P starts to count the cards 1, 2,3.....trails off. T points to each card and asks "what is this?" while holding up a prop (ball, car, etc). T repeats for each card and prop and matches the word to the prop with P's help. T, " very

good, and this one is.....?" P points to correct card for car and T replies "Excellent! Good job, excellent.

- 7. Now C's turn..." P is beaming, huge smile. He is giving the T his full attention and interacting verbally, spontaneously without prompting. P enjoys the props as he is playing with them and reluctantly hands them over to C to match to the words on the cards. P immediately asks the other student (C) facing him, "What is it?" referring to the ball. P picks the ball up from the table again. P holds the ball up and points to it, in imitation of the T's actions with him from just before. C has not seen or responded as he is looking down at the table and the other 'toy' props on it.
- 8. P looks at me as T is checking behind her at the progress the 4 students are making on their 'Test'. I acknowledge him with a smile and then try to avoid further eye contact or possible distraction by looking down at my note paper and then to the T. The T turns back towards C and asks "The ball?" P interrupts and prompts "the yellow ball". The T says (to P) "Excuse me....... its not your turn, you have had your turn." P waits head held balanced in both his hands. He is bouncing his legs up and down and is clearly very interested in the interaction between C and the T as he is leaning foreword and his eyes are following their every movement.
- 9. After a short interval P interrupts again ".......Bus......." which C then repeats as the answer. T dusts her hands off and says "I know that you know, what is this (the question being asked)...... its not your turn......" T continues by addressing C "C! C!........ need to be awake (pay attention). Red, red bus........" C is paying attention now and looks at what the T is pointing at. P is looking at the floor and fidgeting, follows with his eyes a small ant or bug walking along the floor under the desk by moving first his head and then whole body.
- 10. T says "What are you doing......?" P sits up straight again and pays attention to the T who has placed word cards on the table in front of him. T says "Put the..... words in order." The T voice prompts P in choosing the words in the correct order for the construction of a sentence, which he repeats. The Cards are colour coded with some red or yellow. Names of people or objects are in yellow and joining words like 'and' or simple verbs are in red. T says "I'm coming to mark" to group doing their 'test'.

- 11. Then T asks P "Is that Dad?" while pointing to the card he is holding. P replies with amusement (big smile) "No, its mom." T says "ok, so **Mom** and **Dad** are......" P scratches his head and looks on while the T helps to arrange the cards into a sentence. T slowly continues placing the cards in a line in front of P as he fills in the missing words verbally with some physical prompts, like the T pointing at the ball when she puts down the word card for it while saying, "Mom and **Dad** are **playing** with the **ball.**"
- 12. T tells P, "Excellent." P moves to touch the ball. T intervenes, "Excellent, but no...... don't touch the ball." P is getting tired and he is yawning while his eyelids are starting to droop. His eyes do not appear as focused as before and don't appear to be centred which gives him the appearance of constantly looking else where like the ceiling or to the side. He appears to be straining to maintain control of them as he constantly blinks and refocuses on the T. His head is also being held at an angle now and is no longer being kept upright.
- 13. T tells him "Now pay attention and wait its C's turn." P puts his hands in his pockets. Looks down then holds his face in his hands resting his chin on his palms. Hands back to pockets, looking at something in his pocket, then something on his chair. T takes other cards off the desk behind her and says to both P and C, "Today we have cooking." P repeats this after her. T asks "Who likes pizza?" P is not paying attention and is watching the 'test' group with his head turned while leaning back on his chair.
- 14. The T redirects his attention by calling him by name and stressing "What is **this**.....?" While holding up a card with the word pizza on it. T points to the 'p' and stresses the sound 'P'...... in the word pizza. P looks at this orange card with the word pizza on it and holds it to his mouth. (I noted it was not in yellow) He starts looking around, sees me and smiles. I return the smile and look down to discourage any further interaction which could be distracting. T says "I will be back now, just going to check and speak to this group." T indicates the group taking the 'test'.
- 15. P is very interested in what the T is doing with this group. His whole body is leaning forward towards this group with his body resting on the desk, half standing out of his

chair. T admonishes the eldest student in the class, "E....., if you know the answer what are you waiting for....?" T praises another student, "M! very good." T asks M, "Can a bird fly?" M answers with a big smile, "Yes." The test is an activity where the boys have to circle a yes or no after a statement with a corresponding picture as an extra prompt. E.g. A picture of a bird flying with the question Can a bird fly? Yes / No.

- 16. This is a repeated activity as the T says "This is for practice for sharing work" (Previously done in groups). T continues "If you stuck with this the whole day I will not come and help." From this I understand the T to mean she won't help if they aren't trying as its not new work and she knows what their capabilities are. T's body language is not confrontational more a resigned statement based on her palm up, out stretched arms and pulled up shoulders. Her voice is not raised but the tone is firm.
- P is now looking back at the card and wiggling his hands. He is sitting down again and mumbling to himself with a frown on his face while playing with the card. P asks C in a quiet voice, "C, whats this word?" P holds the word up in front of C in imitation of what the T was doing previously. C looks at card then at 'test' group. P is quiet now and checking to see what the T and other group are doing. P touches his mouth again and looks over to me. Appears to be considering what I am doing in the class. P head cocked to one side with a slight frown on his face while tapping the side of his mouth with his forefinger.
- 18. Looks at door, then back at the card, then at me. I make sure not to make direct eye contact. P starts to fiddle with his teeth, finger in his mouth. T is still preoccupied with the other group. In response to continual yawns T tells E to go and wash his face, clicks her fingers "go....go....go...." T goes back to P and C. T asks "What is this?" T holds up pizza card and points at it. T says "Mmmmmmm......" while indicating licking her lips and rubbing her stomach. T continues "Pizza......Pizza" P and C repeat the word after her.
- 19. Tholds up a yellow card with her (first) name on it and asks P "what is it?" P gets the colour first and then the name correct. T continues with flash cards, asking P and C each in turn. T then says "boys, look at this, fast." T shows them cards. P and C answer by pointing at the correct props and/or saying the word. T repeats "Ball, excellent!" P is

smiling broadly at the T, enjoying the game. While T is sorting out the cards P starts trying to get something out of his pocket and fidgets on his chair. T says "P, hand away from your pocket and sit nicely."

- 20. T shows him a card and asks "What is this card?" P repeats the question then puts his finger to the side of his mouth and taps it back and forth. P says "mmmmm...... Let me think."P looks down at the table, not the card. T says "No, don't think what is it. Look at the card." P replies "mmmmmmm.....P." T says "Yes. It is your name, doesn't need thinking!" T holds up next prop its an aeroplane. When she asks C, P makes a sign to indicate flying with one hand and the noise of a flying aeroplane. He interrupts, leaning forward in his chair, appears unable to wait for his turn to be asked.
- 21. T says "yes, now pick the right word." T places three cards on the table. T checks progress of other group. P and C look at the cards but don't choose any. T returns and shows them which is the correct word, 'aeroplane'. P repeats "plane." T says ok "close your eyes." P squeezes his eyes tightly shut, scrunching up his face in an effort to keep them closed. T continues "Put your heads down, sleep.......I'll bring something......" P and C are obviously used to this activity as they both comply immediately without question.
- 22. Both are smiling and sitting very quietly with heads down on their arms on the table, eyes still shut. T goes to small fridge on the side of the classroom behind P. T takes out several packets holds them next to her side out of sight of the students. T places her hand on P's shoulder says "Head upclose eyes." P puts his hands out in front of him without prompts indicating he is familiar with the pattern of this activity. The T puts a tomato in his hands. P laughs out loud. T asks "What is this?"
- 23. P smiling and holding the tomato with both hands, eyes still held tightly shut. T prompts "Touch it with your hands." T helps P to reform his hands over the tomato. P rubs one hand over the top. P smiles and says "Its an apple." P appears to be enjoying the 'game' as he is paying full attention and still keeping his eyes tightly squeezed together. T replies with a question "Is it...?" P is smiling and giggling. P repeats softly "apple.....?" T continues "No....... you can slice it, put it in a salad.......what is it?"

- 24. P shouts out excitedly "Maatoe." T says "excellent!" P opens his eyes and looks at the tomato in his hands, C still has his eyes shut. T repeats the exercise with C while P watches. P is sitting leaning forward in his chair, very interested in how C does with the guessing. P is watching C intently and has a big smile on his face. Holding his head on his hands, chin cupped in his hands, arms resting on the table. After C has had a turn to guess T holds up the tomato and a word card. T gets both boys to repeat the word.
- A boy (B) from the group doing a test has been to the bathroom (which is in the classroom). B comes over to the T. T is busy with P and C, showing them the cards and asks "Boys, what is this......" T sees B and tells him "B, sit down." He doesn't move but hovers and peers over the seated P and C's heads. T says "Don't cover the people." B asks "Where is my paper?....." B indicates he has finished his last paper in the 'test' by pointing to it. T turns her head to see his paper on the desk and then gives him another one.
- 26. B moves off to his chair and starts the work on the new paper. T turns back to P and C. T says "P, closer to the table......push yourself." T indicates with her hands and body language that P must move closer to the table and sit with his arms on the table, centred on his chair and facing the table. During the T's interaction with B, P had been moving his chair slightly back and started slouching in his seat. P pulls his chair closer to the table, smiles at the T. P rubs his eyes and softly repeats the word 'tomato' to himself.
- 27. T puts two cards down in front of P and asks "......now, which word is tomato?......this word or this word?" The T points at each word in turn. P points to the correct card. The T nods and turns to get something out of the bag. P squeezes his eyes shut as soon as he sees the T reaching for the bag and hears its rustling. P puts his hands out in front of him, on the table. The T places a large green pepper in his hands. P is smiling and giggling, clearly enjoying the 'game'. T asks him "what is it?" referring to the pepper.
- 28. P answers "tomatoe.....?." When T says, "No" P immediately guess "apple...?" T replies "no" and tells him "it's a capsicum." P opens his eyes to check. T puts different foods in front of him and tells him "now..sit nicely." P is watching with interest what is being packed from the bag. His eyes follow the T's hands moving from the packet to the

table with each item. He doesn't remain focused on the items on the table for very long and is more interested in what else may be in the bag, spending a longer time focused on the packet than what is actually coming out of it.

- 29. The T refocuses P's attention by speaking to him and drawing his attention to the table. T points to each food item in turn and says, "Now look P........... cheese mushroomstomato for making?" P is looking but makes no reply. The T places cards in front of him The T points to each card in turn, some have the name of the ingredients on them one has 'pizza' on it. The T points to each in turn and P follows her hand with his eyes and head. At the 'pizza' card he hesitates and looks up at the T. She nods and together with P says "pizza" with a slight delay from P.
- 30. P coughs twice. A pause, two more coughs. P is fidgeting with his feet and starts bouncing and rocking them up and down. T is distracted by student B in 'test' group. P wants to tell the T something about the word cards. P points to cards and says in a very soft voice "..... (inaudible) past me...... (inaudible)." After a short pause with the T still turned towards the 'test' group, P tries again still in a very soft voice "Excuse me....sorry...." B is looking at his paper and is frowning as T turns back to P and C.
- 31. B is not settled and continues frowning and mumbling to himself while turning his paper forwards and backwards to see both sides. T turns to P and asks "P. Do you like pizza?" P is happy to have the T's attention and smiles before answering "Wellll you know....." T raises her voice and says "Question.. yes or no!" T is aware of me, looks over to where I'm sitting. I don't make eye contact and the T continues. T waits for P's answer. P is looking down at the table. After a pause the T turns to the 'test' group.
- 32. The T refocuses them by drawing their attention to their worksheet. T settles them down with additional work sheets and turns back to P and C. P is playing with the tomato and talking quietly to himself. He pauses and looks to see what the Arabic group are doing with T2. They are cutting cardboard. P is very interested in this activity, he leans forward to see better, smiles and moves his fingers in an indication of cutting in time with one of the Arabic group students. T returns to P and C's group.
- 33. T places cards out in front of them to form a card sentence. T says "I like pizza." She

points at the cards and looks at P before asking "Which one is this?" P turns his head from watching the Arabic group and looks at the T and not the cards. P answers "I like pizza." T repeats slowly "You like pizza?" "You like pizza." P nods his head and maintains eye contact with the T. T shows P the cards and asks "You like tomato or pizza?" P looks at both cards but only smiles. T asks "You like tomato on pizza?"

- 34. Both P and T have big smiles. T holds cards out and asks "where is pizza?" then T rubs her stomach in a circular action and says "mmmmm...." indicating something good to eat. P is chuckling at the T's actions. He says "P likes pizza." P is looking at the floor and rubs his stomach in a similar but less exaggerated action than the T. T asks P "Let me hear the sound." P continues looking at the floor. T doesn't press any further but turns to C and places two cards in front of him before asking "Which card says tomato?"
- 35. P picks up the tomato and taps it while saying in a low voice "This one." C answers the T and points out the correct card. The T responds with "Excellent!" The T claps her hands and says "Fine." P is interested in the classroom floor and is bent over double in his seat touching it. T notices that he is not paying attention and reprimands him, "I didn't ask you to touch the floor!" She continues "Now revise words then puzzle." P starts to say something.
- 36. T interrupts "Don't say anything just listen.... Ok?" P is looking at T and still has his mouth open "uhhhhh......." T asks him again "Ok?" P says "Yes....." P says "I like Mom." The T starts to pack out some more cards. There are three cards with the first being 'I', the second 'like' and a choice for the third of 'ball, pizza or mom'. The T puts the cards down in front of P and says "Excellent, ok .. again." "Read the sentence." P starts to 'read', "I like pizza." T says "No not pizza. Read the word."
- 37. She leans backwards and turns slightly to see the 'test' group who are generating a fair amount of noise before clapping her hands together loudly and asking "Finished......?" Some of the students nod and the T says "Ok, one more", before giving papers to them to continue with. P continues reading the sentence unprompted, holding his head in his hands, one hand under his chin. T turns back towards P and C and holds up words to make a new sentence.

- 38. P reads "I like plane" when the word is aeroplane and the T points at the group of props on the table to prompt him that the word is one of these. T changes the end card and P carries on reading.... "I like C....." but he uses the incorrect pronunciation for C's name. T makes him aware of the error and corrects his pronunciation. "No.... C,......C." C also says "Yes.....C....." P and T are smiling, T holds up cards again. P has a big smile and sits forward before reading "I like P."
- 39. The T puts the cards down and P chooses the word cards for this sentence. The T laughs and teases P "You like yourself?" She laughs and says "Don't be selfish like someone else as well" while pointing at the other possible card choices. P laughs and lowers his eyes, looking at the options from the side of his vision. T laughs and redirects P's attention to her, "Last one."...... "Open your eyes.......open your ears....... and look at me." The T holds two cards up and asks P "What is this......?"
- 40. P indicates an aeroplane with his hands. T says "No, I don't want that I want a bus." P looks at the red double decker London bus prop. T hands him a puzzle and continues "P you can play with this puzzle till I am free." T tells both P and C but turns towards C "Now C's turn." P immediately and with some force pushes all the cards away from him toward C. T admonishes P "P don't push cards!" P opens the puzzle about body parts but doesn't look inside. Instead he is very interested in something on the floor.
- It has a main body of three large puzzle pieces depicting a cartoon like boy figure with lines radiating from the different body parts to the edge of the puzzle pieces. (Appendix 13) P has to find the matching parts which will continue the line and have the correct picture and corresponding word. For e.g. The line from the boys hair corresponds with the smaller puzzle piece with the identical picture of his head and the word 'head' on it. The line on the smaller piece will match the rest of the line on the large piece as an additional prompt and/or check to ensure it's the correct piece.
- 42. P says "......Bus." T looks at P and says "I did not say one single word and you are practising don't say anything its C's test." P looks back at the puzzle in front of him. The T puts the box cover up as a guide and refocuses P's attention on the puzzle by packing some of the pieces out in front of him. T turns back towards C and holds up P's name card for him to read. P is distracted and very interested in the card, following its

movement with his eyes while holding a puzzle piece back to front (Picture side facing down) in his hands.

- 43. T puts cards down in front of C and goes to collect the 'test' papers from the 'test' group. P smiles and looks over to the 'test' group because C has gone to speak to a particular student and given him the name card with his name on it. P is staring at the other group without facial expression or focused eye movement now. When C returns to sit across from him, P twitches his shoulders suddenly and blinks rapidly for a few seconds. He raises his eyebrows and opens his mouth before looking down at the puzzle piece in his hand.
- 44. After a few seconds of motionless staring at the piece he is holding, he starts to build the puzzle. P finds a tiny elastic in the puzzle box and is insistent that the T take it. Some of the other students from both the 'test' group and the Arabic group start drifting over. The T asks "Where are you going? Going to sport?" P asks "I'm going to sport also well?" After no immediate response from the T he repeats the question. P is watching the T interacting with the other students following the conversation with his eyes and head movement between the participants.
- 45. When the T doesn't respond after a short delay he asks "Lets go to sport too?" T responds with a quick side ways glance to P by saying "Its speech." P looks down at the desk. The T concludes her conversation with the other students and comes over to his table. The T says "I'll give you some parts (of the puzzle), not everything." The T splits some of the smaller puzzle pieces out and puts three in place. P sits still facing the table and looking at the puzzle with both feet flat now. He is intently staring at the puzzle pieces, slowly moving his eyes over them.

46.	T says in a sing song voice to the 'test' group, "I'mmmmco mmming,
	I'mmmmco mmming,, beeee cause I don't heeeee
	ar anythinnnnnnng" The 'test' group are becoming quite rowdy
	and haven't responded to the T. T raises her voice "Yalla ⁷² boys, I'll bring a

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 $^{^{72}}$ Arabic Phrase translated in English as meaning come on, as in get a move on (Informal interview with the teacher 18/12/05).

marker....., to tick or make a big cross." The T walks over to the 'test' group. P carries on with his puzzle undisturbed by the interaction.

- 47. He has his head down, sitting quietly without fidgeting and is moving his eyes from piece to piece. He touches and then taps the side of his mouth with his first finger and makes an audible mmmmmmm sound as If considering an option for the puzzle. During this action/activity he repeatedly moves his eyes slowly between a selected few puzzle pieces on one side of the table. P carries on working with the puzzle by himself at the table. He touches his nose, tapping it in between picking up pieces.
- 48. He appears absorbed in the activity, never looking up at the increasing activity and noise being generated by the other two groups. Instead he is leaning over his puzzle pieces and keeps picking up different pieces to try and fit them in place. T is checking the 'test' group's papers and placing some of them in a folder, she checks on P and C by glancing over her shoulder. She says "I'm loooooo.. king" The 'test' group are stretching in their seats and looking around.
- 49. Quite a few greet me as they are used to me volunteering at the school. I nod my head and acknowledge their greeting before returning it in as low key as possible. I try to avoid eye contact followed by pointing at their papers that the T is putting in front of them for corrections to be made. The T is talking them through some of the errors on the paper. She is discussing the yes no option of the question "Can a ball bounce?" P is still looking at his puzzle but chimes in with "......ball is bouncing...... boing... boing."
- 50. He follows this with a hand motion depicting a bouncing ball, but with a puzzle piece in his hand. P doesn't look at the other table but has started to fidget with his feet and isn't picking up new pieces. He has been holding the same piece since making it 'bounce' like a ball. He starts to play with his feet, shuffling them around and making some noise with them. P puts his head to one side to look under the table at his feet. The T has seen what he is doing but has ignored or not responded as yet.
- P sees a small ant walking on the floor and sits immediately motionless watching its progress. The T now comes over to his table and says "whats on floor?" She bends down to have a closer look which P also does. When the T straightens up so does P. She points

to a puzzle piece and looks at P with her eyebrows raised. P follows her hand then looks back up at the T and says "Tongue....tongue," followed by sticking his out to demonstrate his point.

- T responds by pointing to the large puzzle piece of the boy showing his tongue and says "So follow your finger to puzzle, then......" The students in the 'test' group are getting restless. The T is distracted frequently by requests to go to the bathroom etc from this group and is constantly moving between P's table and this group. P is carrying on by himself but is not picking up any pieces, only looking at the table and moving his eyes from piece to piece at a slow tempo.
- After a few seconds he picks up another piece and continues to look down at the main puzzle. P sighs quietly....... and says "Where does the teeth go......?" The T replies "You find it, Follow the line." P starts to trace the line and the T moves over to the other group again. She looks at their work and asks them "Can a goat climb?" P looks up and answers "Yes......" followed by an explanation of why goats can climb. The T acknowledges that he has given the correct answer and redirects him to his puzzle with a pointed finger.
- P smiles and looks back at his puzzle but shakes or nods his head in answer to the questions that the T is asking the other group. P initiates an answer without a question being asked "Yes, a clown can juggle...." (he appears to be repeating a previously known or commonly repeated activity as he knows what questions are on the test page of the other group even though he can't see their papers.) The T comes back over to his group, looks at his work scanning each placement and says "I'm so proud of you..... excellent job."
- The T points at one piece. P says/asks "Does teeth go here?" while nodding at the T. T raises her eyebrows and asks "You think so?" T points to the piece and taps it "Follow the line......" she repeats twice. P is not looking at her finger so she repeats "Follow the line" again..... and again. P points to the puzzle and then looks down. He is distracted, continually turning and looking at the other children behind him and not making eye contact with the T. She taps the board again and repeats slowly but more loudly "Follow the line........follow the line."

- 56. P looks down to where he is pointing and the T asks "To the bellybutton? You said teeth........" T walks to other group and start to prepare them for cooking which will follow. P is sitting looking at the puzzle, but appears unfocused on the work in front of him. He is staring at the table above the puzzle with a vacant expression and doesn't blink for a noticeable period of time. T is walking between the other students and delegates two to wash the vegetables.
- 57. The T comments to me about the new stand "Look at this nice stand for M" (used for a student with cerebral palsy), and points to it. I nod. P blinks and moves his head to look at the puzzle on the table before looking up and following the T's movements between the other students getting ready to cook. P follows the social interaction between the T and the students, moving his head from one to the other and smiling at the light hearted teasing going on between them. T says "Only one who can push this stand E...... oldest very good E. (I'm) Very proud." T smiles at E who is concentrating on the stand.
- E who is concentrating on the stand and smiling too. P is very interested, focused on what E is doing. P is sitting up straight with both his hands on his head. He asks "Maybe you need a little help?" No response so he follows up with "Let me help you…." while he gets up and makes to move towards E and the stand. T says "No, go and finish your job." P reluctantly sits down and holds his head in his hands looking down at the pieces.
- A pause and then T asks P "Did you finish?" P replies "I got these two......" He points at two pieces and then counts "1, 2," When he does this his voice trails off and he loses focus of the pieces and starts to stare into the distance. The T asks "What about the eye?" The T looks at his puzzle and checks before saying "Big clap for P" P responds with a big smile and is interested in the puzzle again picking up and looking at new pieces but not placing any.
- 60. The T takes the other pieces and says ".....Too difficult for you." P says "I can try." T asks "Are you sure?" P responds by taking the puzzle pieces that are still on the table. P asks "Where does this go?" He holds up a piece. T says "I don't know." She looks at P waits a bit then continues "You said you would try?" After another interval with P just staring at the piece and frowning, the T says "It's a chest...." P tries to fit the piece and

- looks to where the T is pointing. He stands up but still has pieces trying to put them in.
- 61. He manages to put one piece in then starts to pack it up.... Places pieces back into the box. T asks "Did you finish?" P answers "Yeeaaa up!" He continues packing up one piece at a time into the lid then tips the lid into the box, before covering the box. P turns the box over and walks over to me. The T calls him and asks "Finish Peter?" P looks around and nods. T tells/asks "You will help wash vegetables now?..... Will you please show C how to wash vegetables now?"
- 62. P is very interested in being given a task and comes straight over to the T. He says "Sure!" He goes to the basin and takes a tomatoe then speaks to himself "Put it in....." T says "P. I said teach him......" P looks up at the T. T indicates washing of the Tomato with her hands and looks at P before pointing at C and saying to P, "Show him (C) how to wash it." P's eyes follows her pointing to C, he shrugs his shoulders and says "OK" P looks at C over his shoulder and says "Come" T repeats "Come", indicating to C to join P at the basin by making shooing movements with both her hands.
- 63. T looks at P who is washing but not looking at what he is doing and exclaims "
 Eeeeee....! Don't squeeze it (the tomato)." P has a big smile and chuckle but does look
 and takes more care in handling the washing. The T tells the other boys "Come boys"
 getting them to carry on with their respective jobs. P is still happily washing and playing
 with the water while C has wandered off following a few paces behind the T. P has
 almost finished all of the tomatoes when he takes one of the last ones from the packet he
 seems to notice.
- 64. His eyes open wide and he exclaims "Whoa! This pot (Bowl) is full!" P empties the water out of the bowl, puts some of the tomatoes that fell out into the basin back in. He walks carrying the bowl away from the basin and a few steps towards the middle of the classroom before stopping. He hesitates then takes a few paces back then a few forward, he appears unsure what to do. The T says "Mushrooms", holding the packets up. She has her back to P and hasn't seen him yet. He immediately responds "I'll do it!"
- 65. The T turns, takes the tomatoes in the bowl from P and hands him the packets of mushrooms. She tells him to wash the dirt off and then turns to delegate jobs and

instructions to some of the other students, "Clean up" (points to some students), "Move tables." (points to another) etc. P is very absorbed in washing the mushrooms, taking one out at a time and rinsing it carefully turning it from side to side, before placing it on a board. The T notices and says "I want you to use your two hands."

- 66. The T rubs her hands together as an example and says "Wash it....wash it." P uses both hands but only to hold the mushroom and rinse it. The T says "More" and indicates rubbing the mushroom to wash it with her hands. P says "OK" and starts to rub the mushrooms under the running water. He selects another mushroom, holds it up.... Says "This one...." He turns it over and starts to wash it while looking around to see what the rest of the students are doing.
- After a short time he turns back to the basin and takes one mushroom after another to wash/rinse before placing them one at a time into a bowl. He takes one back out of the bowl and rinses it again before putting it back in the bowl again. The T has to speak to him twice to get his attention, repeating "Peter. Look at me." When P looks up at her she indicates rubbing the mushrooms with her hands and says "Your two hands!" P answers "OK." Followed after a short delay by "Teacher (Name) help me." He keeps glancing at the other students to see what they are doing, following their activities with his eyes.
- 68. He appears agitated to get finished, not paying as much attention to washing now but keeps looking over his shoulder. The T comes over looks at his bowl of clean mushrooms, holds up her hand to stop him washing anymore and says "Ok, excellent." The T directs all the students with gestures, tap on the shoulders, pointing and says "Good Boys." She asks "What else do we need boys?" P offers "Cucumber!" P takes something and starts to wash. T says "Thank you, big boy. You put them on the table." (indicating the bowl of mushrooms.)
- 69. P does and answers "Sure...... What about sausages?" The T nods and P says "They need to be cleanLets clean the sausages." T says "Then change the water, this water is dirty." She is referring to the water that has collected in the basin while P was rinsing/washing vegetables under the running tap. The T opens the packet of sausages. P is watching and following her every movement with his eyes and head. P says "......Now...... (as in next step..)" The T gives him the open packet.

- 70. He asks "Yes, Teacher (name)?" She nods and he starts to wash the sausages. He is concentrating and the T rubs him on the back as encouragement before moving on to supervise another student. He finishes and turns to one of the other students who is holding some plastic plates saying "E, I'll take these." The other student passes two plastic plates and P places the sausages on them and puts them on the table. He has his mouth slightly open and frowns slightly in concentration to carry them without dropping any on the floor with a visible tremor and shaking of the sausages clearly visible.
- T says "We will wait for S from speech (therapy)." T tells students "Sit on the carpet." When some look at her with eyebrows raised she answers "Money concept." P is standing at the table unresponsive while all the students except for C are moving to sit on the carpet. The T asks P "P can you bring the mobile from the bag?" P becomes more alert immediately smiles and straightens up his shoulders before asking where it is. The T starts to explain and P moves toward the bag on a side table against the wall of the classroom.
- Once he reaches the bag she starts to guide his search by describing the compartment of the bag "The small one in front Zip....... Small mobile....." The T keeps up a running commentary to direct him. P asks "What does it look like?" He finds the mobile and gives it to the T and tells her he'll take it back and close the bag. The T didn't hear him because after she makes a call she asks P "Can you please put this away?" He replies "Sure." and puts it back, being very particular to close the zip and check it to see that its closed.
- 74. The T tells T2's group to wash their hands. P looks up from the bag where he is still standing with a puzzled look on his face. He frowns and says "I did wash my hands." T

turns and speaks to me. "They are very good today......come everyday...... (T laughs). They are never this good." P turns and tells me "We are cooking today." T notices students crowded in toilet, puts her hands on her hips and says/asks "5 Boys in here!?" P is following the T asking her a lot of questions about her mobile. T tells him to go and sit down.

- P asks "Where's my chair?" Another student answers and P thanks him. He sits down and starts to shuffle around on his chair. When T2 tells some of the other students coming out of the toilet to dry their hands P smiling answers in a sing song rhyme "I did....I did...." He is playing with the tomatoe puree on the table turning the container around and around. When the T asks "What are we cooking today?" he chants "Pizza....Pizza...." He licks his lips in an exaggerated way says "Yooop," indicating the movement or action as he pulls a board toward himself.
- 76. The T asks him if this is better, indicating the small table. P answers in a distracted way, first looking around "Ummmm....... yes" The T holds up pre-packaged and prepared pizza bases. T: "Not makingdoughmaking Pizza. Now our goal is make pizza! Who will start slicing?" P has a knife and points to the top of the tomatoe and asks "So you peel it in?" T nods and P starts to try and cut the tomatoe. T reminds him "Watch your hands!" P doesn't look up but answers "Ok, I will."
- 77. T encourages the students with praise: "Very good P, very good B." The T responds to another student, "No more boards." P answers "Well we can share?" P is shaking more noticeably now with the effort to slice but continues looking up at times to see the T. P turns toward me and says "(name), I'm cutting!" T puts on radio with some local music and as the recorder is near it I have to move it away and closer to the students. T is sensitive to my movement, immediately asking if the music is too loud.
- 78. I shake my head indicating 'no problem', as I don't want to influence the flow of the lesson or cause a change in the way things are done. P and the other students have not appeared to notice the interaction as they still have their heads down concentrating on their 'slicing'. P's slicing is improving and appears as more of a backward and forward motion compared to the chopping cutting he was doing before where he was relying on pressure on the knife to cut and not actually slicing.

- 79. T2 states as praise to P and to reinforce to the other students "P is very quiet and watching his fingers." P responds with a big smile and a straightening up of his shoulders. He sits up straighter in his chair but carries on 'slicing'. T adds "Excellent (leans over him) Very good Enough watch your fingers (when he reaches the end of the tomato)." The T reaches over and starts to place the chopped/sliced tomato onto a plate. P reaches over, holds up his knife and says "I'll do it, I'll do it."
- 80. The T takes the knife while saying: "Let me take knife." P says "Sure.", but T has to gently pull it out of his hand. P doesn't appear to notice, his eyes don't follow the knife. He balances his head on one hand and looks at the other students instead. He rubs his nose, then balances his head on both hands, hands cradling both his cheeks. Now he intently follows the T's hands with his eyes, before following her with his eyes as she goes to another student to give them a turn at cutting.
- When the T is speaking to this student, encouraging them to cut P softly says "I'd like to cut" while moving his hands over each other in a backwards forwards cutting motion. The T takes stuff out to cut including the washed mushrooms. Its not P's turn but he is looking at the mushrooms. He takes a mushroom and turns it over in his hands but holds it in the container. P sits leaning forward in his chair, he wants to cut, moving his one hand indicating cutting of the mushroom he is still holding in the container while watching every movement of the student's hands busy cutting.
- He looks up at T2, frowns, still holding the mushroom and says "Coz I need to cut..."

 T2 explains pointing to the student who is busy cutting "When he is finished." T takes the sliced items and indicates a next stage saying "OK, OK."P has the mushroom in both hands now, pulling the stalk out. He puts it in the container. T asks "Who wants to cut this mushroom?" She is smiling, pretending not to see P's hand go shooting up. P is waving his hand in the air, almost out of his chair, hopping on the seat saying "Me! Me!"
- 83. He is very serious and adds "I know how to slice it, my daddy teach me!" T is grinning and asks him "Your daddy teach you?" P nods and indicates how in the air with his hands. The excitement level is increasing with the students interacting and chattering spontaneously to each other. T2 turns the music down a bit as its adding to the increasing

- noise level. The T gives him the knife to start slicing. She says to the other students "We want capsicum (green pepper)" and waits to see who offers to cut.
- P does not look up he is busy slicing the mushrooms with apparent greater ease than the tomato as he is cutting quicker and finer pieces. The class is one of mixed language so the T says to one of the Arabic speaking boys and P who are cutting their ingredients extremely fine "Yeea, nam! When finished say I'm finished." The T asks "Whos next?" while moving around from one student to the other. P has only a few mushrooms left and is just audible asking "Can I slice? I want to cut"
- 85. He looks at the T waits a short while before repeating "Can I ...?" T replies "Yes.... I will bring the trays." She holds P's hands to get his attention and tells him she will be back just going out the class. T emphasizes "P Listen!" P looks at T's face, his head is lolling a bit towards the side without any expression and he isn't focusing directly on her eyes to make eye contact. The T goes out the classroom. P turns and looks at me when another student notices me and greets me twice. I smile and point at the table to redirect their attention.
- P's face is without expression and appears slack or unfocused. T2 wants him to give the knife but he doesn't want to. T2 explains something inaudible to him and takes it. P frowns and refocuses his eyes on the table before saying/ asking "I want to cut sausages?" The T returns to the classroom. P tells the T her phone was ringing. The T tells him to give others a turn. P looks down, looks very upset and appears to start crying. T asks him "Why are you crying.......? Any need to cry?" P looks up but is agitated and fidgety.
- 87. His face is still downcast and his shoulders slumped. After a short pause the T gives him a turn again. She holds his hand to show him how he should cut finer equal pieces. P looks at the other students cutting, holds his knife up after a few seconds, then carries on cutting sausage by himself unprompted. The T comes back and helps him to scrape the cut pieces into a plate. His board is given to another child now. T eats a piece from the plate but scolds E for eating almost all of his pieces, "E! Shame on you, eating before we are finished bad manners, bad manners."

- 88. T2 also eats one piece. P and M are talking and smiling at each other. Something is funny shared in their discussion as they are both laughing. The T says to all of the students "Finished!? Who's next? Yalla⁷³..." T2 puts the plates down and tells P "P this is you Next, next" He is pointing to where in the queue P's mushrooms are and when his turn will come to use them. T sends C to wash his hands for picking his nose. P sits back against his chair and folds his arm, waiting. After a few seconds he says "I know how to cut mushroom."
- 89. He sees more mushrooms in a packet and is fixated on them. He asks T2, "I'll I'll pass mushrooms to you?" T2 is distracted and notices he is cutting again but doesn't take the knife, just warns P "Watch your finger." P is 'stuck' on the mushrooms and cutting them. He points at the cut pieces and directs (T2) "You can take this." T2 is busy with multi tasking between the students and tells P to wait. The T takes out the pre packaged mini pizza bases and says "I'll give everyone a dough, you put what you want."
- 90. She admonishes E, "E, please wake up." (and repeats x 1) The T continues, "First put tomato paste." P is not paying attention he is cutting and cutting more and more mushrooms. The T notices and says "Enough. Enough (She takes the knife) my dear." P looks up in a daze to see where the knife went, sees the T lifting his board and says "I'll do it", followed by him emptying the board. He then holds out the board for the T and another student's.
- 91. The T continues to hand out the dough bases and confirms the children's reaction with "Yes its cold. Dough was in the freezer." P won't hold the base with his hands. He has it on a plate and touches it with just his finger tips. A student comes in from therapy and everyone greets each other spontaneously. There is a lot of excitement with a lot of noise, laughing, smiling and general interactions going on. T brings some order she holds up spoons and loudly says "Spoons!!" to get their attention.
- 92. P is very excited jiggling and tapping his feet up and down at a fast pace. He takes the tomato paste, frowns, holds it over the dough base and looks at the T who is explaining what to do. With one hand holding over his mouth, and his eyes open really wide he uses

⁷³ Please see footnote 72

his other hand to squeeze paste out over the base. He uses quite a lot of force, squeezing the container in half and a lot comes out. The T quickly intervenes "Enough, enough... (he is still firmly gripping the container), enough, enough" and takes it away.

- P is smiling and says "I need", while moving his hand in the air to show spreading. The T hands him a spoon. He starts to spread the paste around the base first one way then the other in a sort of circular motion. He looks at his pizza, then at the other students and T while he is still spreading the paste round and round. There are ingredients on either side of him which he starts to put on with his spoon. He then sits up straight, and starts looking from plate to plate before he starts to stand up.
- 94. There is something he wants at the end of the table which he wants to fetch. The T tells him to sit but moves the sausages closer. P sits, concentrating on his pizza, mouth slightly open, eyes following his hand motion and movements. The T takes the spoon out of his hand and tells him to use his hands. P talks to himself, directing himself with self dialogue. He has the spoon again and wants to use it to get some sausage pieces. He starts having a conversation with M again. All that can be heard are some of his replies "Sure?!" "This one?" etc.
- 95. They are passing ingredients to each other and making patterns on their pizzas. A lot of smiling and talking going on. P is taking a lot of care about placement of ingredients on his pizza, arranging and rearranging pieces. He is staring at his pizza and eating one piece of sausage after another without even looking at the bowl of sausage pieces he is eating from. T says "Cheese on top! Don't eat P just on the pizza." T2 asks him "Why you don't want this?" T2 points at the green peppers and when P doesn't respond he says "Capsicums?"
- P appears confused or non responsive, makes no reply, mouth slack, staring in front of him at the capsicum plate. T says "P don't ignore me (no reponse or movement from P) look at me" Still nothing from P. T holds out the cheese dish and asks him if he wants it for his pizza. P takes a piece of sausage and starts to eat it then notices the cheese and puts some on the pizza, followed by wiggling of his fingers to dust them off. The T takes out some oil and quite a few of the students ask "Why oil?"

- 97. T2 explains to the students its so the bases won't burn. P looks at the backing tray then at the pizza before adding "Or it will go rotten T2." He repeats this then when he still gets no reply he balances his head, chin first on his hands. He leans his head to one side, eats more sausage and puts some on his pizza. He is getting tired with his eyes becoming more hooded and his body posture starting to slump forward. He doesn't appear as alert as before, with slower more relaxed movements seen when he leans forward and moves his hand back and forth to the sausage plate.
- 98. He is chewing much slower now with longer breaks between taking a new piece and short intervals where he stops chewing whats in his mouth and then starts again. C is talking to himself "No..no....." and walking around aimlessly. T2 tries to stop P eating so many pieces of sausage by saying "P. Wait, wait P." P responds, "Just having a single taste T2." T2 gives P a new pizza base. T says "Tomato paste first boys, it will burn without this paste."
- 99. P is busy with the spoon again spreading the tomato paste in circles on the base first clockwise then anticlockwise etc. All the time P is keeping up a steady stream of self dialogue, occasionally looking at his friend next to him. P: "Now, I'll tell you what I'm going to doetc.... etc", describing each step in a measured sing song voice. The T comes up behind him and rubs him playfully on the head while reminding him twice not to put too much on. The T starts to ask the students "You don't want ...?" Followed by, verbally listing each ingredient.
- 100. P responds when mushrooms are mentioned, "I want mushrooms, can you pass some mushrooms please?" T, "Sure." P continues to build up specific careful layers with careful controlled movements of his hands and clearly preferred areas or patterns of ingredient placements, notably mushrooms and sausage dominate. All of this activity takes place with a constant self direction from P which is evident by movement of his mouth but not clearly audible.

is moving around now. He holds his plate with the pizza on it with one hand. With his other hand he indicates a circular motion around the table as the T described.

- 103. The T looks up notices his pizza and asks him "You don't add anything?" She lists the ingredients again with a question mark raised after each one. When she gets no response she tries to place a piece of green pepper on his pizza and gets an instant response in that P moves his plate away. She asks "You don't eat capsicum?" P gives an emphatic NO and grimaces. The T raises her eyebrows in surprise but accepts his decision with a nod. P asks again "Can I have cheese please?" T says "OK."
- 104. P is very happy, with a big smile on his face he turns and shows me his pizza. I return his smile and point at the table to redirect him. He is eating something off his plate then he walks over to the basin and puts his spoon into it. T2 asks him to sit down. He is still holding his plate and sits. He asks "Can I Can I?" pauses then repeats. (appears stuck) The T says "Can I what?" but gets no response. The T looks at his pizza and says "Get one slice of something else at least." T2 is cleaning a huge mess on the floor where another student dropped his fully laden pizza.
- 105. P stretches to get some tomato pieces. He takes a handful and the T tells him "One slice not hundreds." P lets the others drop, gets one and takes it to the T saying "One slice of tomato T (name)." He then asks the T "You want me to take these tomatoes back?" He repeats this question three times with pauses in between. The T does not respond, and its not clear if she heard as she has moved over to other students. P isn't too concerned as he starts talking to another student and eats a slice of tomato.
- 106. This is followed by fun with his classmates where he is joining in the peer group fun, dancing side to side, laughing and chatting with different loosely forming and changing

groups of students. The interactions are spontaneous and he is engaging others and being approached equally. The T has a large plate with the slices of pizza put on it. P helps, pointing to reminds her "Here is the last one." The T gives him an instruction, "You will help T2 clean the classroom?" P: "Sure." T: "You will stay here?" P looks at the T and barely nods.

- 107. The T carries the pizza out to the next classroom where the oven is, P pauses then runs to the door and looks to see where she went, then runs back giggling. He runs up to B and playfully indicates wrestling asking "You want to 'tackle'?" B smiles and moves on with just a bit of jousting. P stops and says "I'm just going to check on T (name)." T2 calls out "P! Come here please. P can you please come and take this board? The boys are cleaning." P comes over and answers "I'm just going to wash it and bring it back, ok?"
- I say that yes I can see he is cleaning but he needs to go back to the other students to finish 'helping'. The T has returned during this time and after a few minutes she leaves again, taking P and C with her to collect the cooked pizzas from the oven in the adjacent classroom. The T beckons to me to follow after them. On entering the 'kitchen' classroom she circles her hand in the air to indicate the other class there and tells them (P and C) to say hello.
- 109. Then the T starts taking out one batch of cooked pizza and puts them to one side to cool down. After awhile she asks P to help her take them off the tray and place them on a plate. P is excited rubbing his hands together "Aaah Man!" He isn't sure how to start using the lifter so the T tells him to use his hands. He does and exclaims "Yeow!" followed by shaking his hand and blowing on it. The T checks the pizza it is warm but not that hot. She says "Not hot.. not hot at all, use your hands." He does gingerly with just his finger tips.
- 110. "Come on," the T encourages joking and pointing at myself and her saying "Me and (my name) will eat it all....." P smiles and starts packing more pizzas. T then says "Can C take a turn now?" P sees a pizza that has a darker cooked section and asks "What happened to that pizza?" The T says "It's the oven." P is very interested and looks at the pizza more closely then at the oven, before prodding the pizza. T says "I said C, I said

C." P is reluctant o stop now:"Aaawwwwhhh."

- 111. T repeats that its C's turn so P turns to me and says "come and see...... (peers into oven where another batch of pizza is cooking) wow..." He counts "1...2...3...4..., is it ready?" T says its almost ready, but tells P he can take the cooked ones to T2 and then come back. We leave to take the pizzas back. P knocks on the classroom door looking through the door's window at the students inside. He is holding his hands awkwardly in a knot with his fingers crooked as if he is holding something.
- 112. The T asks P if he has money in his hand again. P answers, "No" and the T says "OK."(I asked later and the T explained that on days when the students have tuck P tended to carry his money around in his hands the entire day (Informal interview with teacher 18/12/05). P greets the students and they along with T2 chorus a greeting in return. Everyone is busy clearing up and cleaning. P is playing with the T's apron hanging over a chair. He goes and sits down calling one of his friends to follow him, "Come on B."
- T asks me "(my name) Why don't you tape this (the lesson)?" (as I had asked permission to record previously). When I reply that I am and have been she jokes with the students and says "Careful boys, we have an 'enemy' in the class She is taping....." Some of the students look at me and after recognising me smile, with a few waving and then carrying on with their activities. There are a lot of interactions going on. P is saying "..... I promise" in response to something inaudible the T has said or asked. T responds "Don't keep promising you are fine."
- 114. She asks him something again which I could not hear in the observation or after on the 'digital tape' other than her reminder to P "without promising." The T tries a different tact, pretending to call and look for P although he is responsive and interacting he isn't responding to her question or instruction. She looks all around calling "P? P? P?" Looking at all the students one by one she asks, "Who's P?"P is laughing and dusts his hands before fetching the ketchup and sitting down again. The T says "Oh there you are P, thank you."
- 115. The students all eat pizzas and drink juice. There is a lot of laughing and noise. The T asks T2, "What time is music..... 12?" T2 confirms yes and the T asks the boys to eat

finished and clean up. P is washing dishes, rinsing plates and when another student wants to wash he gives him a cloth and a plate to dry instead. The other students are going to the bathroom in the classroom to get washed up and brush their teeth. P also goes and is in the bathroom for a very long time until the T intervenes to get him out.

- 116. She gives him another cleaning activity, spraying and cleaning the tables. The T has to stop him spraying to much saying "Enough, enough," and pointing to other areas on the table. P is determined to keep spraying and seems unable to stop continually spraying despite the T repeating enough several times. The T removes the spray bottle and P starts to rub the tables with a cloth. He rubs on some spots repeatedly and not the whole table. A 'helper' has entered the classroom to help with cleaning up.
- 117. The helper tries to get P to clean other areas on the tables by pointing them out to him. P can be heard to say "But its so dirty you don't understand" He is very verbal, giving the helper a hard time every time she tries to redirect him. After about 6minutes of verbal sparring between P and the helper, the T intervenes and the table gets cleaned with the T and P wiping up between them. The T wipes the areas P misses. He still only cleans small areas. The students line up in a loose row and start following T2 in groups of 2 or more to music in another part of the school.
- I do not accompany them as I have not been able to gain prior access and therefore permission from the music teacher. When the children have gone the T speaks to me, "Maybe it is better that you do this in my class as I know what and why you are doing this. I understand." The children will be having an academic skill development activity in the form of an interactive lesson on 'money concepts' when they return. I remain to help with the final clean up in the classroom and to give the children a 'break' from my presence. After approximately 35 minutes the children return in small loosely formed groups amid a lot of chatter.
- 119. The class splits into the two groups again, one the 'English' group and the other the 'Arabic' group. P is again paired up with C. The T asks P and C to "Open the boxes, please." She is referring to a box of play money on the table and another of food items. P: "Sure. Let C try?" T: "You try from the other side. Give me the big coins,..... Dhirams.

Keep your hands free (referring to P trying to pass the coins while still holing the box at the same time.)" Both P and C count out the plastic coins one at a time while placing them into the T's hands. "1, ... 2,... 3, ... 4, ... 5." A short pause to pick up more coins and then counting resumes 6-10.

- 120. P is sitting with his back to me so I move and am able to gain a profile view, although limited at times. T tells P "Keep coins with you, give me stuff (Food props)." The T is playing the role of the shop keeper and P and C are the customers. P points at a container and asks "That 1 Dhiram⁷⁴?" T replies "You want salt? (P nods) Take it" P adds "Now Zaathar⁷⁵." T asks to remind P about prices, "How much is it?" P replies "2?" It is the correct answer. All the food items have a large white sticker on their front with a number indicating the price.
- 121. T asks P, "Now what do you want?" P is smiling and enjoying the game, he takes his time looking at one item after another. He says "Mmmmm, let me think", while tappng the corner of his mouth with one finger. The T intervenes after a paused delay and asks "How much is the milk?" P replies "5?" but he is hesitant and not confident in his answer. The T nods and asks "How much do you have?" P is a little more confident in saying "3." This is correct and the T tells him "OK, now C's turn."
- 122. When she turns towards C, P continually interrupts. The T responds with a sigh of annoyance and a firm "No, don't give others a chance always talking, its C's turn." "Now P." P looks down at his feet and doesn't interrupt anymore. The T completes C's turn and turns towards P again. The T tells P "I want to buy some stuff from you....." Now in this role play she will be the customer and P the shop keeper. P is sitting calmly in his chair without fidgeting and is smiling, he arranges the food items and is keen to begin.
- 123. The T points at the first item and asks "How much is this juice?" P is very confident in his role as the shopkeeper and immediately says "3 Dhiram!" The T acts shocked holding her hand to her mouth and exclaims "Very expensive! This juice is 2 Dhiram outside. (Meaning at the shops outside this 'school' shop)" More play acting from the T who puts her hands on her hips and then wags her finger at him saying "You are cheating me

⁷⁴ The name of the local UAE currency unit

⁷⁵ A type of spice common in Middle Eastern cooking.

its very costly."

- 124. The T and P bargain back and forth in a big game that both appear familiar with because P says "Ok you know I'll give you a better price." The T laughs and says "I will only give you 2 (Dhiram), you want it or not?" P is nodding and laughing so much he can hardly take the coins. He starts to count 1, ... 2 and takes 2 coins from the T's hands. The T claps her hands together and tells him she is very pleased that after taking the two he stopped and didn't take more.
- 125. P pauses and then says "Look I'll show you real money" followed by fiddling to get something out his pocket. The T says, "No, just keep it in your pocket." She turns to C and says it's his turn now before pointing at another food item prop and asking "What is it?" P immediately interrupts "Zaathar!" T firmly says "No. Not your turn zip your mouth." She puts her finger over her mouth to show him and reinforce what she has said. P copies her briefly the puts his hand down and looks down with side ways glances at the table and the game props.
- 126. He is waiting but jiggling and rocking his legs up and down. The T turns to P and says "Now your turn." "I want salt and Juice. How much money is that all together?" P looks confused and stares at the props and the money for a few seconds. The T coaches, "First count each one (she points at each item's label namely 2 and 3), then all together (5)." P does this following the T's verbal prompt and gets it correct. The T claps her hands and says "Great job! Well done!" P looks at the coins left and says "Only 1 Dhiram now."
- 127. The new 'teacher' carpenter enters the classroom to collect something. He will be teaching the boys some woodwork skills in the near future. The T smiles and says "Now you are a cheap shop, not cheating me anymore." P giggles enjoying the game and mutual teasing. C's turn follows. The activity is repeated and the T claps hands for C. P says "Bravo C." (C is French speaking not P) The T puts some coins in her hands and looks expectantly from P to C and back. P shouts out "I can do it!"
- 128. The T asks "How much money do I have in my hands?" P, "Eeerrrrr" The T slowly repeats twice "P, listen to the questions again." He does and answers "2" to which

the T replies "Excellent." She continues asking him "Give me anything with 2 Dhirams." P chooses the Zaathar. The T play acts but not in a serious context and pretends to be crying. She says "I'm so poor, only have 1 Dhiram. Give me something for only 1." P correctly for the amount gives her the salt. They both laugh.

- 129. Then the T says she has 3, so he needs to give her something for 3. P gives the Zaathar again. The T says "Good, its 2 but I want something for 3 by itself Ok?" P says "Ok milk!" and gives her the milk. The T says "Yes" and P asks "And Zaathar?" The T answers "No, money is finished." P becomes distracted looking around and starts moving the food items around. The T calls him and tries to keep his attention, "Look, look, (pointing to the props on the table, these are placed in a row facing him in the following order, Zaathar 2, juice 1, milk 3, salt 1),...... P listen."
- 130. The T asks him "What can I buy with 2 Dhiram?" She has also placed some coins in front of him. He chooses 2 coins and points to the Zaathar. His movements are slower now and he drops his arm down to the table afterwards. The T continues "What can I buy for 3 Dhiram?" P takes some coins and picks up the milk before giving them both to the T. Is correct and the T says "Well done...... you will swim next week!" P looks around slowly, then asks the T for "Hot cocoa." (This I see in the next few minutes is milk powder, chocolate milkshake powder and water he prepares for himself.)
- 131. The T says "I will give you because you were so good. P gets up very quickly and runs over to the cupboard above the basin. He takes out the cocoa powder and milk powder. The T tells him to count out the spoons 1, 2, 3 etc of the different ingredients. P does this, messing a bit of the chocolate powder as he is shaking and knocks the spoon on the container's mouth which is very small. He then tries to fill the cup from the Hot water on the water dispenser. There isn't enough water in the reservoir bottle.
- 132. The T tells him he can go and fetch some next door in the adjacent classroom as long as he comes straight back. While he is next door the T speaks to me, "He is really excellent today." P returns finishes his drink and then goes to clean his hands. He sees the toothpaste in the bathroom and starts to make a fuss about not liking this type of toothpaste. He starts to cry. This is a sudden big change from the smiles a few minutes ago while mixing the 'hot cocoa.' T2 tries to pacify him and diffuse the situation.

- 133. Its not working and the other students are crowding into the bathroom to see what the fuss is about. The T comes over and after a conversation with P manages to resolve the situation by placing the toothpaste in the cupboard out of sight. P appears to be more aware of my presence, looking over at me frequently and telling me about the toothpaste wanting me to intervene. Both the T and I tell him that if he is going to use my presence I won't be able to come and do my 'work' in his class again, I'll have to work in the foyer or volunteer in the other class again.
- 134. He smiles and says he is fine now and goes and sits on the carpet with the other students. They are all laughing and playing. The T goes and sits down on the couch in front of the carpet. P and three other students start counting the sock colours on the T's sock. The other children come and join in. Some children leave earlier for the bus. He is getting tired, yawning a lot and getting stuck frequently on a sentence or question etc. The T is keeping him busy with cards that make up a sentence 'I like'.
- 135. She uses a toy ball as a prop. Instead of P reading "I like a ball" he keeps reading "I like Pizza" and repeats it about 15 times one after the other. He holds his head slanted to one side and rubs his hands on his shirt. He is tired of work and is joking with the T. The T tries again holding up C's name on a card so that P should read "I like C." Instead he grins and says "I like a bus." The T laughs and acts shocked and indignant before asking "Is this boy a bus?" P is lying backwards on the carpet leaning on his arms with his head to the side, laughing at the T.
- 136. She continues with the 'game' now asking "Where are his wheels?" and so on. C looks up from his magazine and becomes aware something is going on because his name is being mentioned. He looks from one to the other with a frown. P is laughing hard now and answers the T "No he is an aeroplane" followed by more peals of laughter. The T joins in and then P picks up the ball and says "I like the ball." The woodwork 'teacher' comes in with some machines for the next week.
- 137. P becomes very distracted now, alternating between looking at these and playing with the props etc. The T waits until he is playing with toys and says "School for P stops at 12h: 00. I can't push him more else he starts to cry. I can see he has had enough, sometimes he sleeps in the class. (She points to the couch). Observation ends. I thank her

for her time, confirm arrangements for the next observation and leave.

9.2 Appendix 2 - summarized account of observation two.

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Protocol 2 Researcher VJS

Date 17 December (Saturday) 2005

Setting Specialized Centre/School in Dubai, U.A.E.

Senior Boys Classroom

Classroom age group range 12 - 18

Time 9h: 00 - 13h: 00

Lesson Varied activities across an entire school day

No. of students 11

Teachers 2 (1 male/ 1 female)

Classroom assistant Not present, male volunteer present for some of the morning lesson

Therapist New carpentry 'teacher' present in the morning

Occupational Therapist (Appendix 2:42 – 96) (Appendix 5: 1b-17b)

Gender of class boys only

(When referring to other students in the class I have used letters of the alphabet chosen at random A, B, C etc and then consistently used as a means of identification to provide clarity in the transcript while maintaining protection of their privacy and anonyminity. Similarly adults present where identified according to assigned Code letters as given in the transcripts.) It should be noted that in the UAE the school week runs from Saturday to Wednesday, with Thursday and Friday as the weekend. This is in accordance with the Islamic faith and cultural practices of the country.

Please note: Although this observation took place on a Saturday, carpentry will be scheduled for a Sunday in the future as reflected in the Time table (Appendix 12)

1. The students are settling down after the morning routine which consists of calendar time where attendance is taken verbally and recorded on an attendance sheet. Further according to the Teacher (T) (Informal interview 18/12/05) the Day of the week and date is discussed and visually shown with stickers put on the board as well as a discussion of the day's activities. The latter is displayed as a series of word cards indicating the different activities which are placed in descending order on the board. As the day progresses the T removes the cards to indicate to the students which activity is completed

and what is to follow.

- 2. I am not introduced as I'm a non participant observer, however the children are familiar with me and my presence in the classroom as I have assisted the teacher as a volunteer on previous occasions therefore all observations had an interactive component.⁷⁶ I enter and sit towards the back of the classroom against the side wall for desk activity. (On discussion with Peter's Teacher (T) it was decided that I would join the class for observation purposes after the children had been settled down by the morning routine.)
- 3. The T, T2, a male volunteer (V) and the new woodwork 'teacher' (W) are present. The latter is a carpenter who has been hired by the school/centre to teach basic woodwork skills to the senior boys class (P and his peers) however he has no formal teacher qualification. W only speaks Arabic with English limited to a few basic words. The T or T2 translate as required. (For the sake of brevity and as I am not Arabic speaking I will only note the English translations but will indicate their source.)
- 4. P is observed to be walking around the classroom. He appears distracted and very interested in the woodwork machines present in the classroom. The T has to speak to him more than once to gain his attention and refocus his attention else where. She says "P, sit down please." P turns around to look at her briefly before refocusing on the machines. The T notices and says "Listen to me," I don't want you to go to the machines until they are ready." P is still distracted even though he is now sitting in his seat.
- 5. She continues "I'll give you something to do." The T shows him various puzzles and points to a selection asking "Body parts (Appendix 1: 40-61 and Appendix 13) oretc." P answers "Body parts!" He is coughing frequently and seen holding his hand over his mouth at intervals in between. He may be developing a cold or other illness, alternatively it may be a reaction to the dust from the machinery and wood. (Seen to be present although no 'work' has been observed to have occurred on them as yet.)
- 6. As he is trying to work on the puzzle with only one hand the T tells him to "Use your two

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⁷⁶ Every attempt was made to avoid bias and contamination of observations by only including characteristics that were corroborated by a second source other than the observer, such as the teacher, speech therapist, occupational therapist etc.

hands please P." P sits quietly and works independently absorbed in his puzzle for several minutes. He coughs 2, 3 times in quick succession. He is waving to attract the attention of another student and starts a brief conversation with him which is not audible. The other student does not respond verbally but does make eye contact with P for a brief time. The T points at one machine and explains that it is an "electric saw."

- 7. P has his back to the T but chimes in "For wood,wood," before turning to check. Then back to his puzzle. He leans his head on his hands and looks around at the other students. The T is occupied with some of the other students, settling them down with some activities. P is staring into space before him and frowning. The T translates after each sentence from W and explains further to ensure clarity for the students. Aspects of safety when working with the machines are being discussed at great length. e.g. T: "You should focus on the machine" Etc.
- 8. P turns and listens intently following the T's every word. He is very interested in the machines she is pointing to. All the students gather around the machines except for 4 who are to stay at their tables for now. P is one of the 4 as well as C, B and S. The T refocuses him on his puzzle by moving a few parts around to correct them. She returns to help with the students at the machines. There is a lot of noise and P is distracted, rubbing his face and picking a small spot/scab on his chin, then looking at his hands before leaning his head on them.
- 9. After a short pause he smiles mischievously, picks up a piece of fluff from his shirt and puts it on B's hands. B notices and with an abrupt flick of his hands sends it back to P before folding his hands. P doesn't notice as he has noticed the new volunteer. P shakes hands with him and introduces himself, "Hello, my name is P, (a short pause but he is still holding and shaking hands) will you help me? (P points at the puzzle) "The volunteer walks over and P looks at him and checks for confirmation to his question asking "Ok..... so ok?"
- 10. The volunteer nods and squats down next to P's desk so that his head is closer to P's level when P is sitting. The T is please with the interaction softly praising P by saying "Well done" to him while holding one hand under his chin in an affectionate gesture and to get his attention by making eye contact with him. P is now happier and more focused on the

puzzle. He is smiling and 'talking through' options of the different pieces etc with the volunteer who is only facilitating with a nod, yes or a head shake, no to P's dialogue such as P saying "Lets try this (tries a piece in a slot)..." then points to another choice "Well" etc.

- 11. There is a lot of interaction in this way between the two with P asking many questions such as "This goes here?" when he tries different pieces. P doesn't wait for the volunteer to tell him before he tries but asks as he is putting a piece down whether or not it is correct. P is constantly working at the puzzle and is notably shaking, exhibiting a hand tremor which he tries to steady at times by holding his wrist of the hand placing the puzzle piece with his other hand.
- 12. The volunteer is occasionally pointing to a puzzle piece and some low conversation is occurring between the two. P asks, "See round?" indicating a fit. It is incorrect and the V points to the piece and the body part and asks "This one?" (after P has tried to place it.) P searches for another piece scanning the pieces with his eyes, moving his head from side to side looking the pieces over. He suddenly reaches for one "Here it is!" He places it quickly and looks for another, "Yes!" He takes another and places it with a huge smile.
- 13. The volunteer is now starting to place pieces. He starts taking over doing the puzzle and P sits back leaning against his chair and watches for a period of time before starting to select pieces himself again. In between selecting P appears to be pondering or reflecting on choice holding his head with his chin balanced on his closed hands and his one thumb extended onto a cheek, while scanning the pieces and the puzzle with his eyes. His eyes move between the pieces and then back to the main puzzle for a short pause accompanied by a tapping of his thumb against his cheek, before he moves back to visual scanning of the loose pieces.
- 14. P starts to point to different parts on the main puzzle. The volunteer has stopped placing pieces and is waiting for P. Other than making eye contact with P he isn't providing any prompts. The T intervenes and says to P "Look, look." (and points to the line on the main puzzle) (Appendix 1:40-61) Followed by "P, look, ... follow the line." P and the T's heads are close together as he follows the path of her finger from the body part to the area where the puzzle piece should be placed.

- 15. The T moves on and P hums to himself while placing the correct piece. He is very pleased when it fits and sits backwards against his chair, smiling broadly before saying out loud, "So excellent!" Next he looks at another piece, speaks to himself quietly, head leaning over the table "Now" A lot of self dialogue follows and P appears very focused on the puzzle. After some time he becomes aware of the volunteer still being there, looking up for the first time since the T's intervention and making eye contact when the latter uses verbal cues referring to the colour of the lines on the puzzle pieces compared to the matching ones on the main puzzle.
- 16. P looks down and starts reaching out for more pieces and places one in before looking at the volunteer who says no. P shakes his head but doesn't remove the piece, he just looks at it. The volunteer says "It's a mistake." P's response is to hold his hand across his mouth, frown and quietly ask (himself) "How are we going to?" followed by P taking the piece out. P speaks louder now, "I've got it, this is his elbow here, So lets try his elbow..... check?" The last part is directed at the volunteer as P looks up at him expectantly. The volunteer gives a nod in response.
- 17. P has a big smile on his face now. He says, "Now I'm getting this." P and the volunteer continue interacting verbally before the volunteer moves one part. P takes the box which still has a lot of pieces in it and shuffles them around. The volunteer helps him to look in the box and place the pieces right side up in the box in order to see them all clearly. The T and the carpenter (W) are discussing safety issues regarding the woodwork machines and the students.
- P is very interested when the T mentions some safety aspects that she will be discussing further when the students start taking turns at getting familiarized with the machines. This will be their introduction to wood work as a new activity at the centre. (Please note:

 Although this observation took place on a Saturday, carpentry will be scheduled for a Sunday in the future as reflected in the Time table Appendix 12) P is sitting turned in his chair to look at the machines. Another student pulls his chair next to P to get a better look.
- 19. The volunteer has gone to sit on a chair across from P. P turns back to the table. He

pushes the box backwards on his table and puts all the cards out onto the table. He is just looking at all of them as he places them in a row. When he completes this he exclaims "TA, DA!" and holds his hands out with the palms facing up. The T tells the students they will come up in turns to see the machines etc. P is packing the pieces again. The T asks him if he is doing the puzzle.

- 20. He points at the pieces in the packed out row and answers "We are doing these." The T is not convinced and raises her eyebrows before saying "Really?" P gives a small smile and looks down at the puzzle again. There is some interaction between P and the volunteer. P has a frown on his face and is shaking his head while the volunteer is asking "Is this right?" after each time that he points to one card after another. There is a lot of hand movement and gesticulations going on between the two.
- 21. Then P suddenly sits still, pointing to one piece and looks to the Volunteer for confirmation. The latter nods and P places it. There is a lot of noise and activity coming from the group of boys at the machines and P is watching them. He stands up and puts many of the pieces back into the lid of the box. P asks "What do you think now?" and looks from the T to the volunteer. The T says "Clap hands for boys 'not' paying attention" to calls when being called.
- This is in reference to safety where the students are told not to take their eyes off where their hands are while they are using the electrical band saw even if someone calls them by their name. The T and the carpenter are reinforcing this by turning it into a game with the boys where no matter what is being said they are not to pay attention and not look away from the area of the saw and the close proximity of their hands near the working blade. The students are laughing and enjoying the game and reminding each other not to look.
- 23. P is joining in. The T says "Now P you go try." Various people take turns in calling P while he is busy. The T even tells him its "Mommy calling you" but P just giggles and keeps his eyes and head faced forward. The T tells him to switch off the saw which he does and says "Big clap for him. Good P, didn't look." P is very excited and sits down before asking the volunteer "Did you see me!?" He coughs several times and then still broadly smiling looks at the puzzle.

- 24. He is unfocused on it and moves the pieces around at random and without looking at them. One falls on the floor and he retrieves it. The volunteer is sitting back with his arms folded looking at the activity at the saw. The T walks past P and rubs his head in a 'well done' gesture. P stands up and starts to pack the puzzle away. Excitedly, he is continuously talking while the volunteer helps him to pack up. P directs "Put it in here." Then he quickly closes the box and gives it to the T, calling her to get her attention "Teacher (name)!"
- 25. There is a multitude of activities occurring simultaneously between the students ranging from writing, puzzles, computer (pc) and woodwork. (6 students are at the PC, P is doing puzzle work, C is busy with the woodwork, B and E are working on a writing activity and 1 student is sleeping or pretending to at his desk.) The T asks if he is finished and P is very adamant that he has, nodding vigorously while stating clearly that yes he has. The T indicates he should take some new cards (puzzle) to work with which he does.
- 26. P asks "You want to see?" (them). The T responds "No, its for you." He repeats the question asking the volunteer but the T intervenes to show him and verbally prompts him to start the puzzle. The T continues, encouraging him "Find it, find it P." Followed by prompts and redirections such as "What does this mean P?" in an attempt to help him reason out the order of the puzzle pieces. These are individual small puzzles which consist of cards that have a picture and corresponding word on them where the letters and picture are broken up over separate pieces and need to be put together in the correct order to make sense. (i.e. the correct spelling of the word)
- 27. After P has done one with the T she mixes it up again so he can redo it unprompted or aided by her. He enjoys moving the cards around on the table with a swirling motion. (A finger from each hand on a card, while moving them round in opposite circles to each other.) He places some and the T asks "Does this make sense?" P looks down and fixes the order and explains (not very audible) something to the T. T asks him if he means another one indicating the puzzle box which has other puzzle word cards in bundles.
- 28. P looks and says "I'd like to do" then ponders over the box before taking one and start to take the elastic band holding its parts off. Before he completes this he takes a few more bundles (of cards) randomly chosen, into his hand. The volunteer verbally tries to

redirect him to his chosen puzzle cards and when that has limited success he physically moves the cards in the box further out of reach. P still has the bundle in his hand but has to look at his cards now and says "I don't know how to" while holding his hands out stretched palm up in front of him.

- 29. The volunteer helps him get the cards originally chosen completely free from the elastic and placed right side up on the table. P is now more interested and starts trying to put the puzzle's cards in to the correct order. The T watches over P's shoulder, then comes and sits down next to him. She takes the other bundles out of his hand. P starts to lose focus and play with the elastic that came off the cards. The T says "Put them away now." (indicating everything but his cards.)
- 30. P is agitated and wants something in the box making tentative reaching over motions which he doesn't quite carry through before pulling his hand back. He does this several times in short succession, not clear if its another puzzle or the elastic that he wants. He then packs his cards that are loose in front of him up. He tries to put the elastic back on. The T shows him how by fastening another set which had become loose in the box. He tries again but keeps dropping cards out of his small bundle.
- 31. P is becoming upset and looks as if he is going to cry. He tries again and as soon as the cards fall out he grabs them and tries again. The T says "Put them in my hands." He packs them one by one into a neat pile onto her outstretched palm. His tremor is visible. When he is finished he sits back and puts one hand under his chin, resting his head on his hand's palm and with the fingers holding his cheek. He has a neutral expression on his face. The T asks P "What do you want? Fish?" (she is pointing at words in the box.)
- 32. He immediately answers and nods "Yes!" P appears happier now and starts to smile when he takes the cards from the T. He is shaking a lot more obviously now when he holds the very small cards of this word puzzle. He turns to watch the woodwork machine being worked on behind him. The volunteer gives P a physical prompt by reaching over and putting a hand on his arm. P turns back and looks first at the volunteer then at the cards in his hand. He shuffles through the cards in his hand and says "Now, the fish tail."
- 33. He starts putting the puzzle together. As he completes it the T comes over and asks P

"Can you please go to the blue drawers?" He looks up but doesn't make eye contact. The T continues, "Listen, stand up go to the blue drawers..... when you get there I'll tell you what I need." P is half way up from his chair but remains motionless in this position other than looking from the T to the area behind him that she has pointed at, and back again. He has a puzzled expression and frown on his face with his mouth slightly open.

- 34. The T says "Up, up, up, up," while helping him pull his chair out of the way and using her hands to indicate getting up. P stands up but doesn't move towards the drawers (Chest of drawers). When he continues to stand and look at her blankly without making eye contact, she continues "You don't look at me that's why you don't know." (What to do) She calls him by name twice then pauses and repeats calling twice again to get his attention. P looks at her and walks to the drawers, following her pointed finger.
- 35. When he gets there the T says "There is a white and blue box inside." He opens the drawer and looks at her so she repeats "There is a white and blue box inside." P starts to look inside the drawer and the T repeats "There is a white and blue box inside" again. P reaches for something and the T repeats again "There is a white and blue box inside?" but as a question for P followed by "Do you see it?" P says "Yes" and the T answers "Bring it to me." (which he does with a huge smile on his face and at a brisk walk across the classroom.
- 36. The T smiles back at P and says "Thank you,...... excellent job!" P is very pleased and smiles looking around at the other students. The T asks him "Do you want to eat? Lunch?" He nods yes so the T says "OK, go wash your hands." She turns and says to the other students "Lunch time boys." P counts out coins for the T he has taken from his pocket. He smiles when the T jokes with him and says "You are very rich!" P replies "Mommy gave this to me." The T asks him "How much money did mommy give you?" P replies "Plenty" and laughs.
- 37. P continues to play and count his coins. The students are washing hands, collecting their lunch and/or sitting down at the table. The T is asking the class "Did you enjoy the machine (bandsaw)?" She gets some nods some shouts of 'yes' and lots of smiles. She calls for their attention "Everyone!" then asks "Who cut his finger?" everyone

looks around checking. The T continues "Nobody?"......" Some of the students start to see this as a game and start to laugh and shake their heads and say nobody. The T agrees saying "Yes. Why not?......Because everyone was careful!"

- 38. She then reminds those who haven't yet "Go fetch your lunch." Lunches on days when there is no tuck is supplied from home (Informal interview with teacher 18/12/05) and kept in the children's insulated lunch bags (commonly used in the UAE). Each child has a marked shelf in the classroom to store their bag. The T has to ask P to fetch his lunch again and then again "Go fetch your lunch please!" when he gets half way their and gets distracted by the T, student interaction. P collects his lunch and brings it back to the table.
- 39. He sees the volunteer and says "my friend..... my friend....." He shows the volunteer whats in his lunch box and says "Round balls (indicating round date biscuits." The volunteer doesn't understand him and asks "What do you have?" P offers the lunch box to him but the volunteer says "No, its ok...." P keeps offering him some. The T distracts P and 2 other students by putting red Christmas hats on them with bells on the end. (Only these three are given hats as the T explains to the class that they are the only 'Christian' boys in the class and therefore celebrate Christmas)
- 40. The other students are very interested in the hats and ask the T a lot of questions. P is very happy with his hat, smiling from ear to ear and moving his head from side to side to make the bell ring. The T tells him to come and look at himself in the floor length mirror, she explains to P he can keep it on everyday but can only take it home to keep on Wednesday when the Christmas holidays will start. The students finish their lunch and the 3 students with hats including P go with T2 to have some fun on the exercise machines in the sports hall (A treadmill, stepper and exercise bike). The rest of the class are to have Islamic studies in Arabic with the religious teacher.
- 41. After approximately 45 minutes all the students return to the classroom to wait for the occupational therapist. When they are all seated the T speaks to them in preparation for a visit to a centre for Desert animals which is planned for the following day in the neighbouring Emirate. The T is using visual props of different animal pictures to discus different animals. P is very vocal and spontaneously interactive. The T asks "Can a sheep live in the Desert?" P answers "No, only camels." For every question P answers "No,

only find a camel."

- 42. The T tries again "Where does the sheep live?" P seems stuck on camels and answers softly shaking his head from side to side and looking down at his feet, "Only a camel." The T says to P, "I'll ask you then you answer." The volunteer has to leave. P with a big wave and smile says "Goodbye, thank you for puzzles." As the volunteer leaves the occupational therapist (OT) arrives carrying a lot of supplies etc. P jumps up and runs over to the OT asking "Can I help you?"
- 43. The OT shakes her head and P follows her to the table and sits down. I check with the OT that she is still in agreement with me observing her lesson and taping it. She confirms again that she is. The OT moves to stand in front of the student's table and asks "P, you remember what we were doing last week? She holds up a toy car prop and starts to recap step by step what they had achieved during the previous lesson. (i.e. they had discussed a flat unfolded as yet, cardboard car (Appendix 11: a) and painted it different colours.)
- 44. P had painted his dark blue and then started painting over it in different colours in succession until it turned a dark black blue colour according to the T (informal interview 18/12/05). The OT puts down the toy 'dinky' car on the table and P picks it up and starts to push it back and forth on the table. He has his head slanted to one side and watches the wheels going round and round. The OT notices he isn't paying attention or interacting during the discussion and takes the prop car away.
- 45. She continues holding up an example of the cut-out cardboard car and indicates painting it with her hands, "We paint to car body parts." The OT hands out the painted cars to the students while repeating and indicating painting of each one "Colouring in car (paint)."P is not happy with the car given to him and holds it up asking "Where is my car?" After no response he tries again "Green?" The OT doesn't look up she only replies "No, blue." P continues to shake his head and look at the other student's cars and the pile still being handed out.
- 46. He is touching the other cars and turning them over appearing to be looking for something, maybe his name? The OT finishes and notices P is trying to check cars by turning them over. She tells P "No", and gives him back his cardboard car. She

continues "First one I threw because it was 'scrap'." P mumbles inaudibly before saying softly "OK." He sits down and runs his finger over the painted cardboard surface. Some of the other students that were absent during the paint lesson are set up at another table to paint their cardboard car cut-outs.

- 47. Another student leaves for his music lesson. P has his head to one side and the irises of his eyes appear un-centred and rolled upwards so that in appearance he appears unfocused and half asleep. He is constantly moving his eyes and blinking to refocus. His head is remaining at an angle towards his body. He turns to watch the students at the other table opening small pots of paint and start to paint their cars and paper around it etc. He remains seated but is not happy, with a large frown and downcast mouth.
- 48. He looks at his car in front of him and says loudly in a very upset voice "It's not my car." The OT is trying to explain the next phase to the students and in between giving explanations says "P please wait." She continues to explain about the cars wheels first in English and then repeats in Arabic. P is not sure what he is supposed to do and looks from side to side to see what the other students are doing. He asks the OT something inaudible but related to the wheels as he points to them.
- 49. She holds up one hand palm facing out in a stop sign and replies "Wait......" before she continues with the Arabic explanation. When she finishes she turns and asks P "How many wheels?" He tentatively smiles a small smile and replies "5", holding up one hand with his fingers spaced out. She replies "No, not 5, you don't need 5" while pointing at each wheel of the prop car with her finger but not verbalizing anything. P is not looking he is watching the students painting again.
- 50. The OT continues counting aloud each wheel on the car prop while pointing to it "1..... 2.... 3..... 4" P says "5" without looking. The OT says "No, Not 5. Count again." P turns and counts to 4 while she points to each wheel. OT says "Very good, very good, now put this one down here."(she is referring to the toy car prop, wanting P to put it down and not play with it.) She turns to face all the students, places a big clear plastic packet on the table which contains black plastic wheels and points to the car before asking "How many wheels boys?"

- The students start counting and the OT places some in front of them. P takes some from the large packet. He didn't count them only reached in and took a few which turn out to be 3 when he opens his hand. He starts to count them "1, .. 2, .. 3" then quickly says "4." The T tells him to count again and takes his hand to the packet to take another one after he gets to 3 and has no more on his palm. She then tells him "Count them again, 1 to 4." P looks down at his hand and starts to count softly while touching the wheels.
- 52. He is getting flustered and keeps restarting the count with the first wheel every time he loses track of which wheels he has touched and counted. After awhile he looks up holds up the wheels and asks the OT "Can we begin?" (he is indicating putting the wheels on his car) She hasn't heard him as she has her back to P. He is looking very confused, sitting back against his chair and looking at all the props and loose parts covering the table. He sits unresponsive apart from coughing for several minutes.
- 53. The OT has been explaining in Arabic and when she is finished she starts to check from student to student to see if they are following her instructions. She notices P isn't doing anything and points to his car and the props and says "P yours." She reminds the students about safety "Be careful when handling nails." (The nails are to hold the wheels on the cardboard car.) P replies "Yes" and holds his hand out for nails. The student that left earlier for music returns. P waits then tries to reach for the nails. The OT says "Wait P, wait."
- P pauses then tries again to get her attention "Scuse me" When that doesn't work P looks down and holds the wheel on the cardboard car to try and figure out how it will work. The students are moving closer together into a tighter group around the table. This creates a lot of noise and activity. P moves his car parts closer to his body with his arms and holds on to the wheel and cardboard cutout. He is leaning over them with his body, with both his arms from the elbow to the hands flat and encircling them on the table.
- P is coughing a lot. He is watching the other students and only moves when he scratches his ears, coughs or yawns. The latter two are frequent. The students are settling down and the OT holds up first 4 wheels and then 4 nails while saying "Everyone take up your 4 wheels and 4 nails....." One student puts a nail into his mouth. The T makes an example of him. She points at his mouth and addresses him with a loud admonishing tone "What

is this? What will happen?" The T indicates choking with her face, body and hands, "...... Die."

- The students are all watching her with serious faces. One student shouts out "I don't want to die!" The T says "No nails in mouth!" P nods his head in agreement while saying "You'll die, you know what happened" His voice is drowned out in the students interactions and he trails off before sitting back and playing with his nails on the table in front of him. The OT gives instruction regarding the sequence of construction the students will be following in completing their cars.
- 57. There is a lot of noise and activity between the students themselves as well as to and from the T, OT and T2. P is pressing the parts (Wheel with nail through it) to the card body of the car, he is not waiting but trying to figure it out himself. He is eager to get the car made as he keeps pushing it along the table as if its driving but the wheels fall off as they aren't fastened on properly yet. The nails then keep falling out of the wheels. P tries a few times then holds up one of his nails looks up and around for help, "How do I get mine in?"
- He tries to get the nail into the wheel's hole but his fingers can't get it in. He looks round then tries some more and eventually gets it in but he doesn't let go so when he moves his hand back to pick up another wheel he pulls it out again. When he is trying to put the nail in his fingers are holding the nail very tightly and can be see to become white and red on the tips. With each attempt his tremor is increasing. He is getting frustrated seen when he tries to jam the nail in. After several attempts he sits back and says "I'm waiting"

 The T replies "Yalla⁷⁷ P...... please."
- 59. She indicates she is busy and he needs to wait his turn. P sits back and plays absentmindedly with the nail in his hand while he waits. The T comes over and with her helping prompts he can after several attempts put the nail in the wheel and leave it there. His hands are still shaking quite noticeably but he folds the car with the T's help. The side is difficult for him to fold as it's a small piece that needs to be bent over. P tries then says, "I can't do it." The T isn't sure which parts have to be folded which way and checks with the OT again.

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⁷⁷ Arabic word please see footnote72

- 60. The T returns to help P fold the car parts. T folds the parts and says to P "Push them strong (shows him how to bend them, emphasizing putting pressure to bend the cardboard properly and not just a light fold), strong! Now we will glue them." The T shows P how to squeeze the glue out of the tube. He enjoys doing this, has a big smile on his face and is using both his hands to squeeze the glue tube while the T holds the relevant cardboard folded section. The T takes it and carries on.
- 61. P is very interested in the 3D shape that is starting to form and that it can move. He keeps turning his head to see different angles of his car and is making a moving car motion with his hand above the desk. There are a lot of students interrupting the T, wanting her help, attention or intervention in cases where other students are misbehaving. The T is dealing with this and in one case to stop the tail telling says "B! Not your business." P does not appear to be aware as he doesn't look up or interact with the other students.
- 62. Instead he is playing with the wheels and nails on the table in front of him. He sees the big packet of nails and picks it up, turning it round then up and down before putting it back on the table again. He has picked up his car from the table where the T has left it to deal with some of the other students. P is trying to push the nails for the wheels back through the cardboard. He asks "How do I get this thing in?" while looking around at what the other students, the T and OT are doing.
- 63. The T replies "Leave it we will follow the instructions (she points at the OT who is busy helping another student.)" P pauses then tries to attach it himself again. He has the right concept but isn't applying enough pressure. After a couple of attempts he sits back and yawns, slumps his shoulders and starts to rock on his chair. P looks at his car and says "I can't, ... don't know how to fold." He shrugs his shoulders and rocks a few more times before looking up and starting to play with the wheels and nails set out for the student next to him.
- 64. He is wiggling the wheels and watching the nails balancing through them. The T makes eye contact with him and says "Leave the nails please." She then continues with another student. P holds one hand over his mouth covering a big grin, sneaks furtive glances at the T and continues to push a nail that has fallen out of a wheel softly around the table with his finger tips. The T reprimands him then says "Ok, keep it with you, don't throw

it far away." P picks up his cardboard then puts it down and continues to play with the nail.

- 65. The T takes one of the nails back and gives it to C after putting it in the wheel again. P puts his head down almost to the same level as the table and continues to play with another nail lying there. The T is back helping to refold over all the flaps of the car for gluing. (glue put on previously was done on the T's initiative and not completed or sufficient according to the OT's instructions) The T is doing most of the activity now and the class has become excessively noisy and busy.
- Many students are milling about and nails are constantly seen and heard to fall out and roll around before being retrieved. The mood is one of ordered 'chaos' and heightened excitement levels with the T, OT and T2 trying to facilitate between all the students to complete each stage of the instructions. P takes up the glue tube. The T says "We only need glue (in) one place." She indicates to P where and he obliges. Then she says "Wheels still." Followed by "Its not easy." when she tries to push the nail through the cardboard while keeping the wheel attached at the same time.
- 67. The OT is also trying and agrees shaking her head, "Not easy." After making the holes the wheels are taken off again to ease handling while gluing. The T is looking for more of the glue which P has. She takes it and goes to the OT to see exactly what has to be done to finish putting the car together. Two students start a squabble with one taking the others things and the latter constantly retrieving them. The noise level goes up till T2 intervenes. The T and OT discuss the project and split the children into 3 approximately equal groups to complete the gluing phase of the construction.
- 68. P is in the T's group and she moves his chair around to face hers. She asks him to open the glue. P opens it and squeezes out glue onto the card for the first fold (again). P is being very careful to put the glue in the correct place and is very slow in getting done. Then the T takes the glue and continues to apply glue to the other areas. P reaches for the glue each time she moves it to the next flap but the T says "Wait, wait." P nods his head and waits. When the T puts the glue down he picks it up.
- 69. She looks up sees he has it and says "Put some on in line on edge of board." The T holds

the car while P puts on the glue she then folds the pieces together and presses it down to secure and glue it. She takes the glue from P and turns to the next student "Ready C?" She repeats the gluing, pleased with the results "This is very good." P stretches backwards in his chair to get the glue that the T has put down on the table. The T doesn't look up but is aware as she says "Leave it" She is working with C's car and says "Ok now....." while folding the parts.

- 70. P leaves the glue and says "Sure." He is very interested in what is going on, watching the T's every movement as she folds and holds down different parts to glue them together. She checks P's car and decides more glue is required. This time she holds his hand and guides it when he is gluing as P's hand tremor is quite pronounced when he initially tries himself. The T encourages him to keep pressing out glue and move his hand along the designated path "Ok, Ok...." She then starts to fold it and press it down to get it to hold again.
- 71. When she is finished she says "OK! P look here...... Excellent!" She holds the car up for him to see, points to one part and says "We still have one more." (indicating 1 more part to glue.) P reaches for the glue and the cardboard car that the T is holding but she says "Wait... wait." When he still continues trying to take the car she says "Wait means wait.....put your hand away." The T has both her hands occupied holding down a part of the car while waiting for the glue to 'take'. P sits back and waits holding the glue.
- 72. The T requires more glue and indicates to P to put some on which he does. Then he has to wait again, followed by more glue needed again. The T indicates this by holding the car towards him and pointing with her finger to where she needs him to put glue. They have their heads together and there is some inaudible conversation going back and forth between them. At this point P puts the cap back onto the glue tube. He is smiling and happy with the one to one attention from the T. P asks "Who wants the glue?" He looks around and places it on the table near the next student.
- 73. The T gives him his car and asks "Could you please press now?" She wants him to apply pressure to the glued together flaps until the glue has dried enough to hold them. The glue is a quick dry type but not instant or super glue for safety reasons and possible remodelling if required to rectify errors. (According to the OT's earlier instructions etc)

The T shows him where to hold and P says "I'll try" before gingerly taking the car with his finger tips and holding it. He keeps swapping hands and rubbing his fingers muttering something about "sticky stuff."

- 74. He puts the car on the table and rubs his hands behind his back. Then he puts them back on the table to play with the glue tube. Its is C's turn with the T now but P doesn't want to wait. He keeps asking "How do you put these in?" while holding up the wheels. The T is busy so the OT answers "Not now, we don't have to play with these now." P still continues trying to put the wheels on so the T says "P, please press your card (she points to where his car has started to come undone)to get it to dry."
- 75. P puts the wheel down and starts to play with his Christmas hat. The T says "I asked you to push pieces together." P replies "How?" The T responds "Like I showed you" P looks at the car and then at the T before asking "How do I squeeze it again?" A pause then P asks again. The T is distracted working on C's car and says "Yes?" P asks her again how he should squeeze it etc. She replies "Like this" and demonstrates using the other student's car she is currently working on.
- P tries and is busy holding and pressing the card car in several places for a few minutes. With a sudden movement he puts it on the table and shouts out "T (name)! I think I did it." The T is busy with other students and with the considerable noise in the classroom does not appear to hear him. P starts playing with the wheels on the table again. P is intently watching student C putting the wheels out flat on the table and then putting the nails through them so that they are standing facing up balanced at their base by the wheel. (Looks like little cupcakes with a single candle on each.)
- 77. The T thanks C and he repeats thank you. However it comes across as something less polite as English is not C's first language so between the OT and T2 joining in to correct C's pronunciation and the inevitable laughter that follows, C gets a lot of attention. This results in quite a lot of interaction with C repeating the 'phrase' continuously to get the same reaction of laughter and joking while the adults try to prevent the other students saying it and get him to say something else.
- 78. P does not appear to be aware of all this activity as he doesn't look up from the nails and

wheels he is busy playing with on the table. He tries first getting one nail into the wheel in imitation of C's wheels and when that is unsuccessful he puts it down, picks up another nail, looks it over and tries it in the same wheel. He does this a few times then looks at a nail and mutters "You'll die?" before putting it back on the table again. He sits back in his chair and absentmindedly scratches his face while looking around at the other students.

- 79. Then he stands up picks at some fluff on the table and throws it on the floor. P moves over to C and prods him lightly on his back. C immediately reacts by shaking his shoulders as if he is throwing or shrugging off an insect. P is giggling and holding his mouth with one hand to stifle the sound. C turns to look at P. Another student is playing with the end of P's hat. P notices and starts to swing his head from side to side to make the bell at the end of his hat jingle. He reaches over and tickles C under his chin.
- 80. Then he looks over to see what the OT is doing. He is very interested in what she is doing for a brief time, staring and following her hand movements. P loses interest and turns to tease/joke with C again. C doesn't appreciate the attention from P and buts his hand up in a sharp jerky motion, palm facing out towards P in a 'don't touch me' or 'keep your distance' stance. The T notices this sudden movement and intervenes. She is trying to teach P and C tolerance for each other, "to be nice" to each other and "not to tickle." (i.e. appropriate peer communication)(Informal interview with teacher 18/12/05).
- 81. The T says to C "P loves you. He's kidding." P pipes up "I'm just tickling you." He shrugs and holds both hands palm facing outwards at his sides, level to his waist with his elbows bent. The T says "Khallis⁷⁸ P. He doesn't like it." P isn't convinced and puts his hand towards C who immediately reacts moving backward, making warding off or brushing away movements with his hands and sounds of protest to get the T's attention. The T repeats "He doesn't!" P says/asks "He does?" P is frowning and looks from the T to C and back again.
- 82. Then he watches the T gluing before looking at C again. The T sees where he is looking and says firmly "P leave him. He doesn't like tickling." She lifts her hands up in a mock gesture of despair at P's persistence and smiles when saying "What to do!" P

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⁷⁸ Arabic word meaning completed or finished etc.

smiles and repeats "What to do" followed by C repeating the exact phrase as well. All three look at each other and grin. The T shakes her head at both of them and says to no one in particular "They don't like each other." She turns and looks at me, nods her head and says "Really!"

- 83. P is still bothering C by speaking to him and trying to explain verbally and with expressive hand movements. The latter seem to bother C the most and he is getting crosser and more irritated all the time judging from his increased volume and frequency of complaints to the T, verbal responses to P and body language. The latter is evident in the way he is crossing and uncrossing his arms turning his head away to indicate ignoring of P when he is talking and dismissive hand waves.
- 84. In contradiction to this from time to time C will turn to look at P and smile which encourages P to continue. This is resulting in a perpetuating cycle of behaviour and reaction etc. The T gives P the toy car prop to distract him, "Look at this nice car." This distracts P for a few minutes as he pushes the car up and down on the table. Then he leaves the car and bothers C again. P is smiling and joking with C but he is not finding it amusing and wants to be left alone. C tells the T "Tell him stop!"
- 85. C turns to P and shouts "Stop!" He pushes P and says "Stop please." P thinks he is playing and smiles and giggles. The T intervenes, "P. P, the man in the red hat?" When P doesn't respond she becomes firmer and says "P look at me! (he makes eye contact) Stop!" P continues to stare at the T and she says "Khallis! Finish! P stop!" After a brief pause he responds with an unrelated comment of "You can hear my bell" followed by moving his head from side to side to make it ring.
- 86. The T tries to get his attention by reaching over and touching his hand, then taps it twice, "Excuse me P." P does not appear to notice and reaches over to try and tap C on the arm. The T repeats "P... P...." He stops and looks at her. She says "Thank you for listening P." P starts to explain something to her which isn't clearly audible. He is being very verbal. The T responds with "I know you are trying to help him but he doesn't like it." After a short pause she carries on with "Ok, wheels on?"
- 87. P responds "Ok, wheels on the bus go round and round" where he sings the last bit

and makes circling motions with his hand while holding a wheel with a nail through it. He drops the nail out on the floor and the T collects it and puts it back in place. She helps him line up the wheels and tells him to push them through (again but this time he has to do it whereas before she did). P grimaces with effort as he starts to push in the nail of the wheels through the cardboard. The T encourages him "push" then sees his grip is starting to slip so stops him "Wait, wait."

- 88. She gets him resettled "Sit nicely first. Use your two hands" etc. He completes attaching the wheels with her help then smiles broadly and starts to play with the finished car. P is fascinated by the completed car, turning it over and over and examining it before running over to show T2 and myself. He then runs to the OT to show her "Look." She replies "Good. You have done the wheels already." P nods and answers "But.. T (name) helped me." All the students have completed cars now and are pushing them around and making car noises.
- 89. The students have become very excited with the noise becoming excessive with students pushing cars and letting them crash into each other with accompanying sound effects. P picks up a car on the table, looks it over and says "This is C's car.... C (calling him)?" T says he is in the bathroom so P answers that he will put it on the table for C. When C comes back out P follows him around (C is taking a book off the top of a cupboard that the T had taken from him earlier and put there). Then P notices a toy aeroplane (used as a prop) and picks it up. P has this in one hand and his car in the other.
- 90. He holds the aeroplane in the air making it fly and makes the accompanying sound effects. There is a wooden puzzle on the same side table where the aeroplane was. It has large pullout wooden cutouts with small centre handles. P notices it in one of his downward 'flight paths'. He stands next to it and starts to unpack them. When they are all out he says "Ok" and starts to pack them in again. It is a very basic easy puzzle. When he finishes he walks away and joins a few of the other students wandering around the classroom.
- 91. He goes over to the carpenter (woodwork 'teacher') and follows him around, peering around him to see what he is doing and matching his every movement in order to continuously position himself to maintain a better view of what is going on. The T

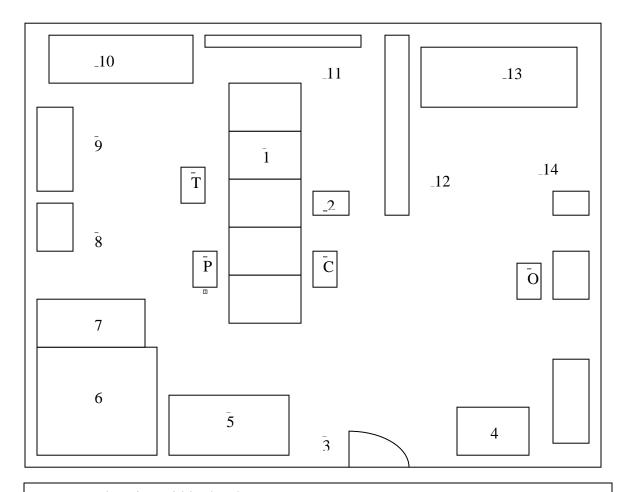
notices and tells him to go and sit down. He goes over to a Christmas card with his name on and packs it into his bag. The OT looks up and names each student walking around followed by asking them to come "Back to the table please."

- 92. The T notices and claps her hands loudly several times. She then calls each student by name and says "Come and sit down." She pauses till everyone is seated again then says "Everyone show me your cars." The students hold up their cars and she visually scans to check, fixing where required. A common problem is the bottom of the car which is folded closed but comes undone easily when the students push the cars along the table and exert a bit of pressure down on it. The T says to one student "Close it, has to be closed...." (She is referring to the bottom of the car)
- 93. P sees this and looks at his car which isn't undone. He then pushes his car on the table, picks it up, and checks it again. When he repeats pushing it along the table it comes undone. He tries to fix it but applies to much pressure and the wheels start to come undone. This is happening with some of the other students as well. The T is fixing cars with more glue. The students are becoming very excited with cars coming undone and wheels with nails popping off and bouncing on to the table and floor.
- 94. The T reprimands them and reminds them of the discussion they had earlier about safety and consequences that could occur i.e. injury etc. P adds "T, C has a book!" The T had removed the same book from C earlier when he had not been paying attention because he had been to busy paging through it. The T doesn't hear or ignores this comment. She is reprimanding one student who has continued to 'play' dangerously with the nails, flicking them at the other students despite the T's warning. The T reprimands him saying "You not going home, very dangerous!"
- 95. The T asks everyone "Try to find any nails and wheels on floor." The children echo an ok and all get down on the floor to look, some squat down some lean over in their chairs etc. P gets up and looks under the table where he finds something. He shouts out "I found a nail! I found a nail!" He gives it to the T and takes his Christmas hat off to pass to her as well. She smiles and says "No..... tomorrow again. (indicating he will wear it again) Wednesday (the last day before the Christmas holidays) you can keep it."

96. P shrugs an ok and goes to collect his bag. All the students are packing up, saying their goodbyes and leaving for the bus etc. The T sees each one out the door. Observation ends. I thank her for her time; confirm arrangements for the interview and leave.

9.3 Appendix 3 – Classroom layout when students work as an entire group.

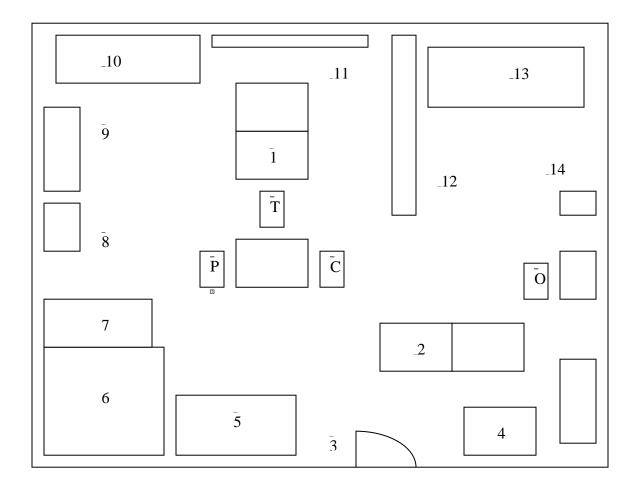
9.3 Appendix 3 – Classroom layout when students work as an entire group.



- P- Peter's location within the classroom
- T- Teacher
- O- Observer/ Researcher
- C- Peter's fellow student
- 1- Entire Group of students
- 2- Arabic teacher or T2
- 3- Double door class room entrance. (Small windows along this wall near ceiling.)
- 4- Personal computer
- 5- Storage shelves for schoolbags
- 6- Bathroom access through class room
- 7- Wash up area
- 8- Refrigerator
- 9- Chest of drawers
- 10- Shelves/ storage of props etc.
- 11- Whiteboard. (Small windows along this wall near ceiling.)
- 12- Book case room divider
- 13- Couch with carpet in front of it
- 14- Television and video
- 15- Cupboard for storage

9.4 Appendix 4 - Classroom layout when Peter works as part of a small group.

9.4 Appendix 4 - Classroom layout when Peter works as part of a small group.



- P- Peter's location within the classroom
- T- Teacher
- O- Observer/ Researcher
- C- Peter's fellow student
- 1- English Group of students
- 2- Arabic group of students
- 3- Double door class room entrance. (Small windows along this wall near ceiling.)
- 4- Personal computer
- 5- Storage shelves for schoolbags
- 6- Bathroom access through class room
- 7- Wash up area
- 8- Refrigerator
- 9- Chest of drawers
- 10- Shelves/ storage of props etc.
- 11- Whiteboard. (Small windows along this wall near ceiling.)
- 12- Book case room divider
- 13- Couch with carpet in front of it
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- 15- Cupboard for storage

9.5 Appendix 5 - summarized account of Semi-structured interview based Questionnaire: Case study of Child experiencing LGS

9.5 Appendix 5 - summarized account of Semi-structured interview based Questionnaire: Case study of Child experiencing LGS

(a = class teacher b = occupational therapist c = speech therapist)

Questionnaire: Case study of Child experiencing LGS

1. What is your experience working with a child with LGS or severe epilepsy?

- a) With severe epilepsy yes, not LGS. This is my first case. (Teacher's teaching experience 9years)
- b) No, similar cases. One may have been LGS. The child had severe epilepsy and it (the epilepsy or seizures) wasn't controlled. (Teacher's teaching experience 2 years)
- c) Severe yes, not LGS, till now. (Therapist's teaching experience 15 years)

2. What are your feelings regarding teaching /working with a child with LGS or severe epilepsy? (tests? Formal and/or Informal Etc)

- a) Now its ok. To be truthful in the beginning, with Peter, I went to the headmistress to complain. I felt I couldn't keep him in my class. It was so difficult.
- b) Its theory first then practice. First very challenging, a lot to take into account, reading, interview the family etc then how to provide my service. I want to keep up the level, but also need to adjust it. E.g. What
 - kind of stimulation will be enough for the child's programme without overdoing it but still be of value? Also when the seizures are uncontrollable its destroys your work, months of it and you have to start building again.
- c) Scary in the beginning. With the first case I was shocked. It was terrible to see and (back) then I didn't know what to do. I was just running around with this little boy in my arms looking for someone to help. Now I know better, what to do etc, and I'm ok with, it but I've never forgotten it.

3. How long have you worked with Peter⁷⁹?

- a) Since he joined the centre, everyday. I've been his class teacher almost two years now.
- b) About six months now but not individually, always as part of the group. All the students in his class.
- c) Almost for one year now. He comes to my classroom once a week for about 30 min. Its on an individual basis one to one.

4. How would you describe his weaknesses and/or learning difficulties? (Examples)

- a) He doesn't understand unless he gets clear instructions, very clear. The steps must be short and very organized. He also needs touch (prompting) and a relationship (with the person trying to teach him etc). Not as a baby, he needs verbal interaction. He learns with play, practical examples are very important then the verbal too.
- b) His inability to remain engaged. He is ok in a group but needs specific attention to maintain him within his work. He also needs his own safe area, his own space when with the other children, else he gets jittery or gets preoccupied with them.
- c) He is very set in his ways, you have to find a way around because he gets stuck, or wants the same etc. We were working with a card game 'people who help us'. From the beginning he wanted the music band card he had remembered from before. Then when we get to, now all mix them up, no. He wants music band so no cooperation, do I push it or go round? To reach my goal for him I go around.

⁷⁹ Pseudonym used

5. How would you describe his strengths?

(Examples)

- a) Verbal, he has good communication. He has a lot of background information which he uses in conversation in the class etc. He is self organized about his things. His stuff is kept nicely and his memory is good. Its easy now, when he is happy.
- b) When motivated he makes a good effort. He is social, not afraid. Its not hard to build rapport some children won't work with new therapists but he doesn't mind new people like that. When he is listening he can transfer verbal into actions in the activity.
- c) His language. His vocabulary is very wide.

6. In your opinion what are his educational needs?

- a) He needs academic skills but functional e.g. when teaching money concept generate it to practical examples like props and the Mall when we go shopping etc. You need to 'brainstorm' with him to bring the topic back and refocus him.
- b) Short, brief 'shots', intensive for any subject. Delivered in structured brief time, no more than 30 minutes, after that he doesn't have high tolerance. Alternate methods or he gets bored. If you don't vary your tone every 3rd or 4th sentence you can see him slip away.
- c) He needs to practice social skills in group situations and manage unfamiliar situations independently. Peter needs to develop successful following through with instructions for simple tasks or errands when he isn't supported one to one.

7. What educational support are you able to provide him with?

- a) Everything 1 to 1 or help him with peers. Help him to support other children and they help him, C and P help each other as peers. Also self care issues and independence.
- b) Fine motor development like lace tying but in activities with some academic, but small stuff, reading and self initiated grasping. Including sensory and motor integration-copying from pattern, repeating what he sees and continuing the pattern. E.g. 'sewing' different shape, texture and coloured beads on to a string in a specific order where a short example of the sequence pattern is given on a card.
- c) Encouragement to share information with his class, and responsibility to bring his work unaided when I come to collect him and then to return (walk back to his class) on his own after our time, help him with sequencing in a story using cards with pictures and then building sentences.

8. How would you describe Peter's Temperament?

- a) Very friendly when he isn't tired. He can be moody so conditions very important at home and school, he is involved with his environment, interactive.
- b) Friendly, always wants to help.
- c) Very social 1 to 1, he likes to chat and tell stories about his weekend etc.

9. What has been the most challenging aspect of teaching and class management with P?

- a) He gets stuck when not happy. He can't focus, can't do work. Happy and healthy is important! Good days are the best day for teaching.
- b) Safety issues when deciding on a programme or exercise, always that fear with kids with epilepsy, even for professionals (Drs), don't want to stress him, he is very dependant and influenced by his environment, but need to make him 'stretch' a bit, so lesson structure also as he won't sit for whole hour. Work for 15minutes then go and comeback again etc.
- c) Keeping him focused and on task especially when he isn't having a good day. Getting him to move on to another activity when he likes the one already completed and wants to repeat it continually and exclusively.

10. What has been the positive and/or rewarding aspect of teaching and class management with Peter?

- a) He is very sharing and social, very social. He loves the boys and jokes with them.
- b) He will usually always make an attempt or try the activity without needing to be pushed or prompting.
- c) He is very interactive in our sessions, sociable and volunteers a lot of information etc.

11. What implications have arisen from this situation within the classroom?

- a) Not focusing on other children at times because he needs me 1 to 1 a lot, C too so difficult. His IEP⁸⁰ is different from the rest. The rest have similar IEP's e.g. all have numbers 1-100 to count and work with Peter has 1-10. He can't be left to independent tasks and he needs more play in learning so puzzles, starter skills. His rewards are different, more physical and immediate, they have to be practical not praise. Like stickers but won't wait till end needs to see it put on immediate during not end of activity.
- b) Regular modification in the lesson to keep his attention and motivation to carry on. Have to have a lot of help available like the teacher or volunteers because he needs 1 to 1 a lot of the time to remind him what is expected.
- c) The lesson has to be modified and made shorter and simpler if he gets stuck or additional parts added, replacing others to match his interest and vocabulary. Some things have to be negotiated if he is really being persistent or doesn't want the lesson to end and pack up.

12. What learning style and/or teaching approach have you found to benefit him the most?

- a) Practical, (kinaesthetic). Playing, learn with play, brainstorm by asking questions and puzzles.
- b) Visual and verbal, hands on, short activities .Demonstrations and examples, one to one. Children with epilepsy need to feel safe, contained, not wide variety, always structure else over stimulating.
- c) Making things fun to learn, with visual props, humour and stories which bring activities alive and make them relative to him/his family etc.

13. What is the current curriculum type offered? (responsive etc?)

- a) Interactive, practical based when possible. Also theme based, the whole school follows a theme like e.g. transport for a set time so there is reinforcement when students see the notice boards and art work in the halls from other classes. The curriculum is adapted to each student.
- b) Interactive, I take activities from various sources, multi sensory. It is designed per child, not curriculum way it is but adapted.
- c) Interactive topic based learning, loosely based on the British national curriculum but very adapted.

14. In your opinion how is the current curriculum able to meet his needs?

- a) At the centre its not at his level but brought down as much as possible and adapted to fit.
- b) The curriculum is made flexible by the staff, changed for each student to what they can do its not a strictly followed system and the assessments are according to individual IEP goals.
- c) The class teacher differentiates the work so that he can access the curriculum at an achievable level; tasks, games. A lot of repetition and consolidation is offered in class. I provide enrichment, so that he can develop his 'reading', with symbols to support it. Also look at sentence development, sequencing, sequential thinking with cards etc. We all work to the same theme and adjust the curriculum to it.

15. What would your recommendations be to further support this child's learning?

a) You hav	e to understand him	give him a chance	treat him as a hig l	hov so stop at time.	s and talk to him
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⁸⁰ Individual education plan

- In the beginning not now, I was shocked. We had a very big gap to understand each other. Now we have rules and discussion and consequence (work or behaviour contract Appendix 14). Its very clear for all and Peter needs it to be very structured.
- b) These are the last few years for this class and Peter as children with special needs before they become adults with special needs. So they need to have as a minimum a baseline or be equipped with skills to face the community, leisure activities or productive work Issue related to this need to be considered and developed.
- c) He needs to practice social skills, go and ask, small tasks, things to do like teenagers. After a weekend he could put his verbal thoughts visually into speech bubbles so he can remember and put into a sentence, then he can tell his news, nicely and interesting to his class to help his communication skills talking to a group. Individually its fine but the group communication needs work.

16. What is your opinion about inclusion for P?

- a) Yes, but needs one to one shadow. (The presence of a full time teacher's assistant, in class, who could support him through activities) Also a very qualified general teacher if he is to be included and it takes time to understand him.
- b) I am newly qualified so the other staff say I still have 'fire' because I believe in it, needs to be done right though. Everyone needs to be equipped and supported to get flexibility for all. The child may need extra from us but in context of mainstream school. Problem here is we don't have legislation so can't interfere and give support. At a conference I attended last year the speaker spoke about the normal variances between all people in society so all will benefit from being in the same social group even if academic level is limited "not everyone has a PhD but everyone has friends." Its should be an equal chance to access all in the community.
- c) Yes, dependant on school and support etc. Also depends on country's system. Here (UAE) teachers in main stream not strong enough as inclusion will depend on the teachers one year to the next to cope with all the different levels. He is missing pieces so normal methods won't work, no usual feedback to work with and build on. Also in secondary schools what do you go by age or education level? There aren't specialist here in mainstream so no easy access (you can't run to a therapist in school as there aren't any to fix it) If the child is in mainstream he will still need therapy but now its after school so extra.

17. Is there anything else you would like to add?

- a) Really I am surprised how well he is doing now from the beginning. He doesn't leave anymore, he listens and follows instructions now. I can leave him for a short time in the class and he stays.
- b) I haven't worked long enough with Peter or individually to add more at this stage.
- c) Peter is very happy at school and proud to be a 'young man' with a homework book (his dialogue diary) and friends. He takes his homework seriously when ever I ask him to bring a picture etc. As soon as he sees me he fetches his diary and any homework unprompted says goodbye to his class and rushes past me to get to the therapy class.

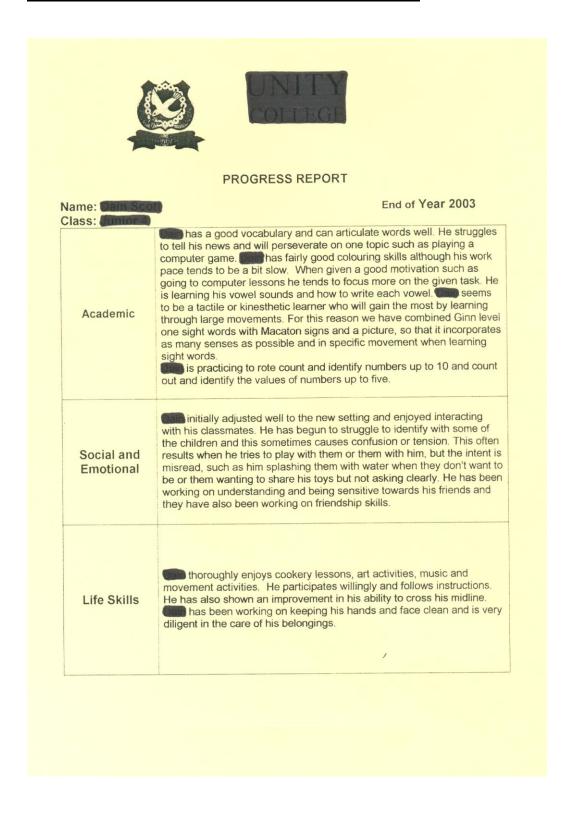
9.6 Appendix 6 – Peter's IEP Speech and language therapy.

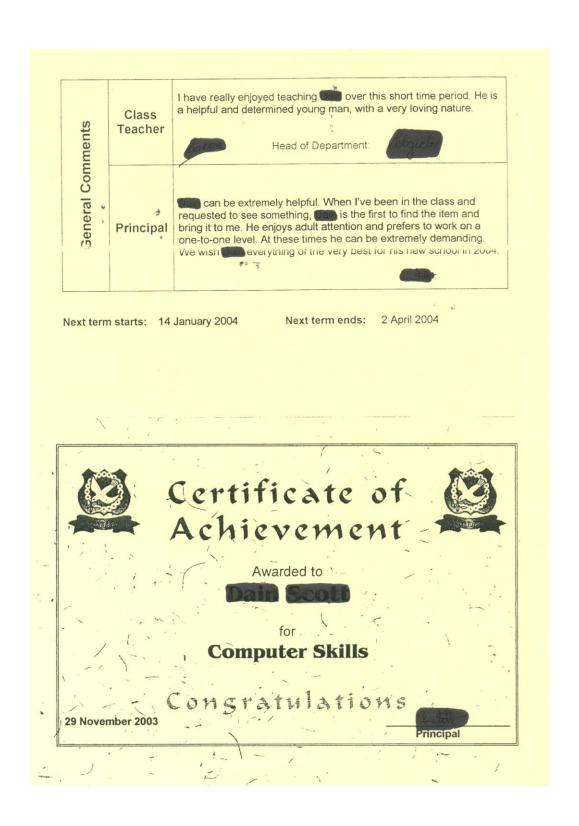
9.6 Appendix 6 – Peter's IEP Speech and language therapy.

Student's Name:	F	Therapist's Name:
Subject Area: Sheach and Language therapy	-	N/S-Naode Supervision
	N/S A	78.2
Term Objectives		Comments
wil be more aware of the need to make eyecontact		
when he is speaking. Gentle physical and verbal prompts		100 ppg - 100 pp
will be given.		
will develop a small sight vocabulary. Simple words		
from the class topic "animals" will be chosen as		
target words, and words like she-in-on		
3 We'll work ons sequential thinking with logical stories of		
5 and 6 pictures and make them visual with key words		
and symbols.		
4 We'll work on semantic-pragmatic language skills such as		
what goes together or the odd one out, matching and sorting		
5 We can use pictographic symbols to make schooltrips and		
reports on the weekends more visual and comprehensive		
for		

9.7 Appendix 7 - Peter's documents from previous school.

9.7 Appendix 7 - Peter's documents from previous school.





9.8 Appendix 8 - Peter's general IEP current year.

9.8 Appendix 8 - Peter's general IEP current year.

CENTRE	
Student's Name:	
Student Information:	gri day
Date Of Birth: 21st Apr- 1992.	
Date Of Initial Placement:	
Current Academic Year: 2005-2006.	
Current Placement: boys.	
Student Study Team:	_
Class Teacher:	-
Art Teacher:	
Music Teacher:	
	-
Therapy Input:	
Group Language Therapy:	
Individual Language Therapy:	
Swimming:	
Sports:	
Additional Information: I tried to focus on his concepts and cognitives stills.	
also I tried to fecus on his social stills specifically.	
	0
	1

will read the letters by using the thash cards. will read the letters by using the thash cards. will read three rames of his class nates depending on his sight memory. such as summing pool art, music depending on his sight memory. will read sunt such so use it every day like bus dad, mum. will read sunt excess with simple differences between them. will practice copying by name. will draw zig zon shapes to start writing later on will draw zig zon the letters. will join the dats from left to right and from later on will join the dats from left to right to left.

Maths. Maths.	
will re-arrange other views such as house sun-mountain will create ahouse by giving him the part to cat and will bollow the right relation of copyling such as it will bollow the right relation of took brush and pasted will show an understanding to the humbers concepts will show an understanding to the humbers concepts will show an understanding to the money concepts will show an understanding to the money concepts will show an understanding to the money concepts will show an understanding to the numbers concepts will keep practicing standing the numbers. It within allow will keep practicing tracing the numbers.	
will create ahouse by giving him the part to cut and will bellow the same system of copying such as a will bellow the same system of copying such as a will use many colours with his colouring not just greet will colour within a transfer function. Maths Will use many colours with his colouring not just greet will cut an line. (every time). Will show an understanding to the numbers concepts will show an understanding to the repunding money concepts will show an understanding to the repunding the right numbers will keep practicing about the numbers. Will show an understanding to the repunding money concepts will show an understanding to the repunding the right numbers. Will show an understanding to the numbers concepts will keep practicing should be the numbers. Will keep practicing tracing the numbers.	re-arrange other views such
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Maths- Will use many colours with his colouring and paste will use many colours with his colouring and paste will show an understanding to the pumbers concepts will seep practicing counting the numbers will keep practicing tracing the numbers.	the material wall be supply the same such as
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will keep practicing tracing the numbers.	will keep proficing quating
will keep practicing tracing the numbers.	Charle of the District deep line
	will keep practicing tracing the

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+	* How Did State Death	The and
	* What is inside my head?	Colourifull
+	* What make me sheeze?	encyclo pedia
+	* How many bones do I have?	classiii
	Secial shills.	
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	noticinases has aline of	needs
W	wait wait for number in the reception with the	Stills in his
7	word where.	ctical
υ٦	will take othern for playing, and give the class make	

Student's Name:	Name:	
An	Annual Goals for the Academic Year September 2004 to June 2005	Key to Evaluation: /= Completed X= not done or not completed
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	D DIS PIONES OFFICE LINCOLLING	TOTS .
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9.9 Appendix 9 – Range of Common Characteristics associated with LGS

9.9 Appendix 9 – Range of Common Characteristics associated with LGS

As a result of all observations, extensive conversations with his teacher, therapists and family, several characteristics both positive and negative have been identified. These were further verified where possible through supportive and relevant literature. Many of the characteristics are seen to be medication related (81) but due to the nature of LGS (Freeman et al. 1997:115) numerous other factors may be interrelated or causative. These characteristics are reflected in the designing and developing of his IEP (Appendices 6 and 8).

Identified Characteristics associated with Peter's LGS:

- Frequent and varied seizures (Freeman et al.1997:61-69,115) (Besag 2004:S5) Most problematic at present is the actual Loss of time and learning in class due to absence seizures, appearing as 'Daydreaming' behaviour⁸².
- Hand Tremor due largely to medication making fine motor skills such as writing very difficult and frustrating for Peter.
- Peter often does not make eye contact unless reminded and encouraged too.
- Bouts of Hyperactivity followed by lethargy, with Peter occasionally falling asleep in class (Appendix 1:137). Lowered energy levels may be due to medication or possible seizure activity (Camfield and Camfield 2002:31; Walker and Shorovon 1999:42).
- Insomnia and disrupted sleep patterns ('Autistic like' characteristics found in LGS) (Boyer et al.1981 cited Besag 2004:S5).
- Easily distractible, inability to maintain focus and reduced attention span. Seen when he is unable to focus on most tasks for more than a few minutes or follow short sequences, and his tendency to wander off from the group during outings in particular (informal interview with the teacher 18/12/05).
- Dizziness, Slurred speech, Unsteady motor control and gait (Walker and Shorovon 1999:42).
- Behavioural issues such as mood swings, going from being cheerful to very quiet and tearful or emotionally withdrawn, occasional aggression⁸³, often coupled with Confusion⁸⁴ (Freeman et al.1997: 63) and possible depression (Datta et al.2005:195) although the latter is not confirmed.

http://www.emedicine.com/neuro/topic186.htm
 A period of altered consciousness but no loss in overall body tone

⁸³ Often associated with confusion related to Status Epilepticus

⁸⁴ More prevalent after a seizure

- Delayed responses/ reactions. Peter appears to take longer to process and respond to stimuli and verbal communication including instruction (Walker and Shorovon 1999:42).
- Inability to filter incoming stimuli hence poor tolerance of crowded and noisy venues
 ('Autistic like' characteristics found in LGS) (Boyer et al.1981 cited Besag 2004:S5)
- Perseverance Single minded behaviour related to a particular situation or task regardless of the outcome or attempts by care giver's reasoning of alternatives. Peter appears to fixate on one point at a particular moment in time. ("He often gets 'stuck' on colour wanting to use one colour for everything or seen when he won't take his jacket off even in extremely high surrounding temperatures and obvious personal discomfort, he is sweating profusely and becoming very flushed") (informal interview with the teacher 18/12/05)
- Resistance to change or new situations. ('Autistic like' characteristics found in LGS) (Boyer
 et al.1981 cited Besag 2004:S5) Peter needs the same sequences or he becomes quite agitated.
 The children normally swim twice a week and if this is cancelled or moved for logistical
 reasons, Peter would be very upset and repeatedly ask when is swimming, becoming
 increasingly agitated as he can't accept any reason or explanations given.
- Curiosity and 'love' of machinery, 'gadgets'. This is a positive aspect as he always
 approaches the class computer and when given a task or appropriate educational software is
 able to maintain focus and interact with the programme for a considerable time
 independently.
- Impaired memory recall (varied uneven short term long term recall) mixes up days and time
- Extreme Difficulty in learning to read or write .Poor Retention and/or frequent loss of
 previously learnt skills resulting in lowered academic or educational progress. Skills have to
 be frequently re- taught.
- Poor judgement regarding personal safety, a reduced sense of danger. Peter will run across a road etc ('Autistic like' characteristics found in LGS) (Boyer et al.1981 cited Besag 2004:S5; Camfield and Camfield 2002:31)
- Lower level of understanding concepts, often he can't accept reasoning.
- Inappropriate social skills for age and/or context, Poor impulse control (Camfield and Camfield 2002:31)
- Heightened sensitivity of the skin to hot/cold (exaggerated response) Apparent higher pain threshold, possibly due to the sedative nature of the medications ('Autistic like' characteristics found in LGS) (Boyer et al.1981 cited Besag 2004:S5)

- Allergic, usually skin reactions and Toxicity related to medication (Walker and Shorovon 1999:42)
- Uneven skill development (generalized not specific to an area). Peter has good verbal skills with an extensive and mature vocabulary yet he is unable to spell or write. Reading is very limited to a few sight words. He was observed to sound out letters with prompts but was unable to blend or put sounds together to make a word. Poor motor skills, in particular fine motor
- Double vision, Drug induced vision processing issues (visual tracking etc) (Walker and Shorovon 1999:42)
- High absenteeism and frequent injuries often requiring hospitalization or medical attention, weakened immune system.
- Nausea⁸⁵, due to medication or Aura⁸⁶ (Walker and Shorovon 1999:42) seen when Peter won't eat a previously indicated favourite food.
- Initial, and often prolonged significant weight loss. 87 This can reverse to weight gain over time if reduced activity levels are more prevalent and/or medication is changed. (Walker and Shorovon 1999:54)
- Loss of control over bodily functions, including speech and motor abilities in some cases due to post seizure period.

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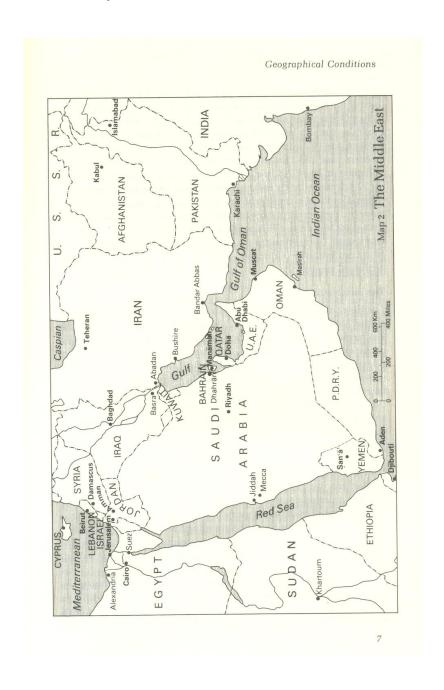
A possible cause of weight loss and poor appetite related to medication
 The precursor to onset of a seizure, perceived as an 'ominous feeling', headache, etc

⁸⁷ Due to interaction of Numerous medications used in conjunction

9.10 Appendix 10 –Maps of the UAE (a and b).

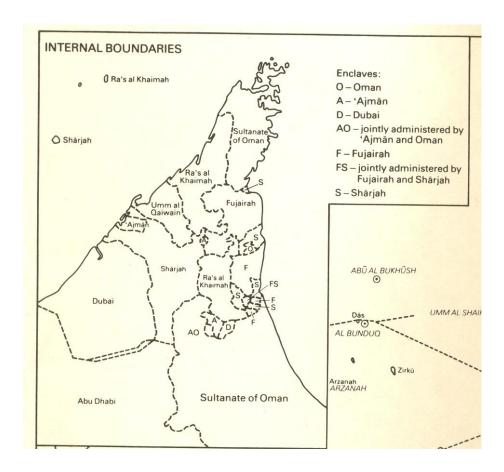
9.10 Appendix 10 –Maps of the UAE.

a) Map indicating positioning and location of the UAE in relation to its neighbours (Heard-Bey 2004:7)



9.10 Appendix 10 –Maps of the UAE.

b) Detailed map of the UAE indicating the separate Emirates (Heard-Bey 2004: i).



9.11 Appendix 11 – Examples of Peter's work (a b and c).

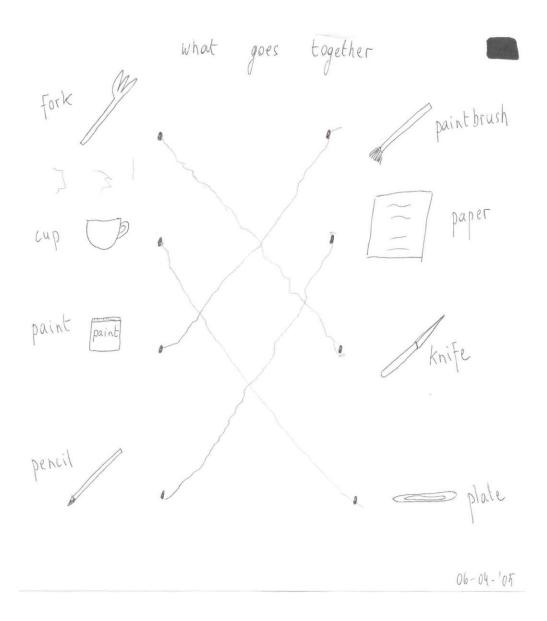
9.11 Appendix 11 – Examples of Peter's work.

a) Example of Car made by Peter in occupational therapy lesson (Appendix 2: 42-96).



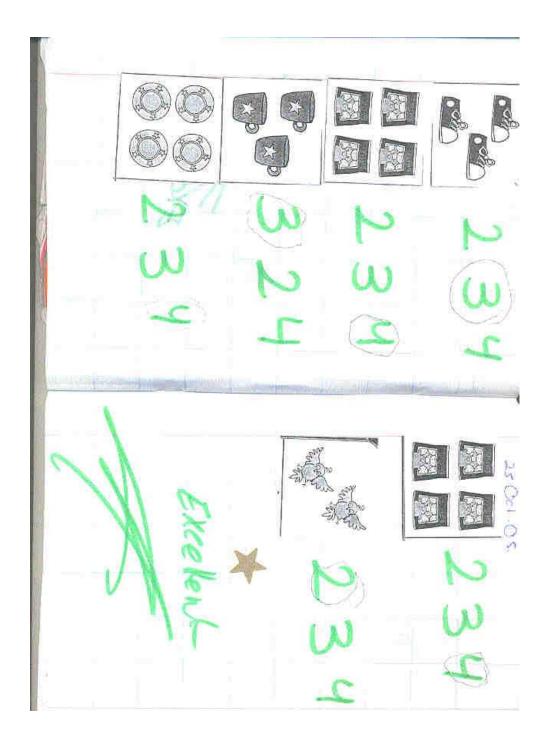
9.11 Appendix 11 – Examples of Peter's work.

b) Examples of work done by Peter in speech therapy



9.11 Appendix 11 – Examples of Peter's work.

c) Examples of Peter's class work



9.12 Appendix 12 – Fixed Weekly timetable of scheduled class activities per day.

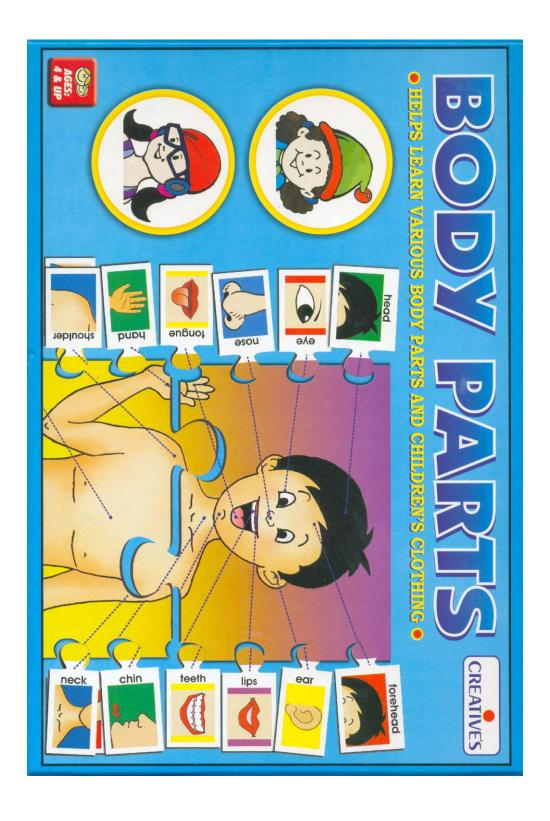
9.12 Appendix 12 – Fixed Weekly timetable of scheduled class activities per day.



Time	SATURDAY	SUNDAY	MONDAY	TUESDAY	WEDNESDAY
8:00- 08:30	Teacher's time	Teacher's time	Teacher's time	Teacher's time	Teacher's time
08:30- 09:00	CALENDER	CALENDER	CALENDER	CALENDER	CALENDER
09:00- 09:30	ACADEMIC	CARPENTARY	MUSIC THERAPY	GYM	ACADEMIC
09:30- 10:00	ACADEMIC	CARPENTARY	ACADEMIC	PLANTING	ACADEMIC
10:00- 10:30	ART	CARPENTARY	ACADEMIC	PLANTING	COOKING
10:30- 11:00	SNACK	SNACK	SNACK	SNACK	COOKING
11:00- 11:30	RELIGION .	ACADEMIC	DAILY LIFE SKILLS	SHOPPING	SEWING
11:30- 12:00	RELIGION	MUSIC	SWIMMIMG	SHOPPING	SEWING
12:00- 12:30	OCCUPATIONAL	GYM	SWIMMING	SHOPPING	MUSIC
12:30- 01:00	OCCUPATIONAL	GYM	SWIMMING	SHOPPING FEEDBACK	FINE MOTOR SKILLS

9.13 Appendix 13 – Puzzle of body parts

9.13 Appendix 13 – Puzzle of body parts



9.14 Appendix 14 – Peter's work/ behaviour contact with his teacher.

9.14 Appendix 14 – Peter's work/ behaviour contact with his teacher.

