

Title:

'Hidden voices': an exploratory single case study into the multiple worlds of a 15 year old young man with autism.

Submitted by Stephen O'Leary, to the University of Exeter as a thesis for the degree of Doctor of Education (Special Educational Needs) by research in December 2011.

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Stephen O'Leary, December 2011

For Nana

“The invention of madness as a disease is in fact nothing less than a peculiar disease of our civilization... We have yet to write the history of that other form of madness, by which men, in an act of sovereign reason, confine their neighbours, and communicate and recognise each other through the merciless language of non-madness... We must try to return, in history, to that zero point in the course of madness at which madness is an undifferentiated experience, a not yet divided experience of division itself... To explore it we must renounce the convenience of terminal truths, and never let ourselves be guided by what we may know of madness... Then, and then only, can we determine the realm in which the man of madness and the man of reason, moving apart are not yet disjunct; and in an incipient and very crude language, antedating that of science, begin the dialogue of their breach, testifying in a fugitive way that they still speak to each other.”

*Michel Foucault
Preface: ‘Madness and Civilization’
1967*

“It was the Special Olympics, 1968, in Seattle. Eight athletes were at the starting line. And, low and behold, they were all going for gold, silver and bronze. And the gun went off and they all started going for the winning line- a hundred yard dash. Then the last little girl fell, and she cried. The second last little girl looked back. She saw a girl down, and she stopped. And the whole auditorium stood up. After that, the other six kids- stopped. And what did they do? They all went back, and they all linked hands and they all came across the winning line together.”

*Pat Falvey: ‘Sean’s Awards Night’
2010*

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ABSTRACT

This thesis presents a 31-day case study carried out with a 15 year old young man who has classical autism. The study involved introducing him to a number of new and challenging activities, in a variety of contexts, over 31 days, that were previously assumed to be outside of his range of capability. The case study found that the application of the concepts of choice, control, challenge and risk had an unexpectedly positive impact upon the young man's performance. This study further attempts to explore the concept of narrative as a 'pedagogical bridge' between the 'worlds' of autism and neurotypicality, arguing that narrative may provide a 'way in' to the world of autism. 'Narrative', this study contends, may provide a tapestry across which the world of autism may be connected with the world that surrounds it; by revealing a multiplicity of selves in a multiplicity of contexts. Methods of data collection included field notes, interviews, photographs and film footage. Ultimately, the study found that the use of 'performance texts' (DVDs featuring the young man's achievements) constituted a powerful means of celebrating his accomplishments within the school and its wider community. Research approaches were participatory and ethnographic in the data collection phases, while a more phenomenological approach was adopted in the data analysis phase. The overarching analytical framework was that of 'narrative analysis' in telling a story of bravery, courage, hope and optimism.

CHAPTER 1- INTRODUCTION

Professional background

During my 11 year career in special education I have worked with children from as young as 5 years of age, to adults as old as 60, with a range of special educational needs which have stemmed from what might some term ‘high functioning’ conditions such as dyslexia, mild general learning disability and Asperger syndrome, to more permanent life-long disabilities, such as visual impairment, hearing impairment, autism, muscular dystrophy, cerebral palsy and stroke. It has been a relatively short, but awe-inspiring career, one that I have been truly privileged to have experienced. I have- for some reason- always been drawn to people, a phenomenon explored in my doctoral studies as ‘the case study’. Everything and anything I have learned- of real meaning and significance- in special education- I have learned exclusively through people- children, teenagers and adults of extraordinary bravery, character, selflessness and fortitude. Like Temple Grandin’s former teacher and mentor, William Carlock, I have been lucky enough to have “*seen the human spirit at its best*” (Grandin & Scariano, 1986: 7).

In September 2008, I accepted a job- a rather unique challenge- to coordinate the development of a new ‘ASD unit’ in a Cork city post-primary school (Nagle Community College)¹ that would cater for pupils with ‘low-functioning’ autism, something that had not before been piloted in an Irish mainstream post-primary school. However, it is important to acknowledge that I was not the first person to develop a ‘special needs unit’ connected to a mainstream school in Ireland for pupils with autism. Within the primary school system (which in Ireland caters for children from approximately 4-12 years of age) ‘units’ or ‘special classes’ for children with disabilities and special educational needs have been in operation for over 3 decades. Table 1 below presents the latest available statistics in relation to the distribution of pupils with autism across the various forms of educational provision in the Irish Republic.

¹ The management of Nagle Community College, as well as its wider managing body the City of Cork Vocational Education Committee, have given their full unreserved permission for the school to be named in this thesis. In addition the reader will notice that certain real names (including those of Sean, his family, and certain project participants) feature throughout thesis. Those people who are named in this thesis are named in accordance with their fully expressed wish to be named. The issues of confidentiality and anonymity are fully discussed the final section of chapter 3 of this thesis (‘Approaching ethics’).

Table 1- Distribution of pupils in forms of ASD provision (adapted from Parsons et al, 2009)

<i>Type of provision</i>	<i>Number of pupils with autism in type of educational provision- 2007/8 or 2008/9*</i>
Mainstream Education	2,571 pupils in general classrooms*. 198 pupils in autism specific classes.
Special Education	170 pupils in general SEN classes*. 101 in autism specific classes.
Home Tuition	500 pupils educated in the home.
July summer provision in the school	78 participant schools (numbers of participant children unknown)
July provision ('home tuition') in the home	1650 pupils
Total estimated number of pupils in educational provision	3,540 pupils aged 5-18 years

It is important to note that originally 'special schools', as well as 'special classes' for those with 'special needs' attached to mainstream schools in Ireland, largely emerged simultaneously during the early 1970s. 'Units' for those with 'special needs' (as they exist today) were not initially envisaged or conceptualised as potential avenues towards inclusion or integration- but were rather simply 'special needs' buildings attached onto 'mainstream' buildings. The point at which potential connections and intersections between 'special' and 'mainstream' education first manifested themselves in Ireland, the point at which the 'inclusion debate' took hold, may be traced back to 1993 when Justice Rory O'Hanlon ruled that Article 42 of the Irish Constitution directed the State to provide an *appropriate* education for *all* children, regardless of disability (Casey, 2000). Subsequently, the task of considering what constituted an 'appropriate' education for school-goers with disabilities and special educational needs was handed (by the Department of Education and Science) to a 'Special Education Review Committee' (SERC) which, in 1993, recommended that "*in so far as possible, appropriate education for pupils with SEN should be provided in ordinary schools*" (SERC Report, 1993: section 1).

Two things subsequently happened within the primary and post-primary school systems in Ireland. Within the primary school system, integration expanded between the 'unit'/'special class' and the 'host', mainstream primary school, whereby children would spend some of the school day in the 'specialist' environment and some of the day in the 'mainstream' environment. Meanwhile, post-primary schools (which cater for young people between the ages of 12 and 18 years approximately) enlisted a system of 'resource provision'. Table 2

below lays out the current DES (Department of Education and Skills) system of resource teaching allocation as it currently applies to Irish post-primary schools.

Table 2- Allocation of resource teaching hours per disability in mainstream schools
(Adapted from DES Circular Sp.Ed. 08/02)

Low incidence disabilities	Hours of resource teaching support available per week
Physical Disability	3
Hearing impairment	4
Emotional disturbance	3.5
Severe emotional disturbance	5
Moderate general learning disability	3.5
Autism/autistic spectrum disorders	5
Specific speech and language disorder	4
Severe/Profound General Learning Disability	5
Visual Impairment	3.5
Assessed Syndrome	3 to 5 depending on the level of general learning disability
Multiple disabilities	5

Ultimately, this system of ‘resource provision’ (resource ‘teaching hours’) was put in place with the intention of assisting pupils with physical, emotional, learning, and sensory difficulties/disabilities to assimilate and ‘fit’ into a mainstream, ‘normal’ school setting. It is a classic deficit-orientated approach, the assumption being that the remediation of ‘within-child’ deficits or shortcomings would equip pupils with ‘special educational needs’ with the ‘skills’ to participate and achieve within a set of mainstream academic norms.

Within this model of ‘withdrawal’ resource provision, teaching contexts are limited to one child, one teacher and one classroom in targeting the child’s academic deficits. In developing the ASD unit I was particularly interested in exploring new ways to strive towards the stated aim of the Education for Persons with Special Educational Needs (EPSEN) Act (2004); namely- to *“assist children with SEN to leave school with the skills necessary to participate to the level of their capacity, in an inclusive way in the social and economic activities of society”* (section 1) via a new ‘model’ freed from the constraints of the traditional model of resource provision. In ‘Facing the Challenge’ (O’Leary, 2011: 24) (which will be discussed in chapter 5) I asked *“what real benefit is it to an adolescent with autism to spend 5 hours of the school week sitting in a room with one adult, focusing on academic targets only when a*

central focus of any educational programme for a person with autism should be to encourage their socialization with other adolescents?”

In responding to this new opportunity, the ‘model of provision’ that I subsequently developed over the following 3 years was essentially a ‘three-tiered’ approach. Within the school building itself pupils attended a reduced number of mainstream subjects in accordance with their individual strengths and interests (such as English, art, PE, woodwork, metalwork), while simultaneously receiving ‘specialist’ provision in the special classes (in areas such as literacy, numeracy, social maths, technological literacy, music & performance, ‘circle time’, ‘chat time’, occupational therapy, speech & language therapy etc.). A third major feature of the programme was the dedication of one-third of the school week to out-of-school activities relating to areas such as health and recreation (swimming, gym work, walking etc.), ‘social literacy’ (attending live dramatic performances, libraries etc.) and ‘orientation skills’ (accessing public transport, practising walking routes around Cork city etc.).

By the end of the programme’s third year the unit had reached its maximum allowed capitation of 12 pupils (who came from both special and mainstream primary schools), had received government funding for a state-of-the art purpose built extension (including sensory rooms, IT facilities, kitchen, sensory garden- in the process making the full school wheelchair accessible), as well as 9 full-time staff (4 teachers and 5 special needs assistants [SNAs]). Through word of mouth alone, the programme was gaining local and national attention. It was praised by local senior academics and senior government ministers as a ‘model of best practice’ that they maintained should be emulated by all schools considering the development of an ASD unit.

Genesis of this thesis

By late 2009, I was reaching the end of the taught modules of my part-time Ed.D (SEN) at the University of Exeter, and was considering what form my final thesis should take. The answer seemed obvious- a ‘model of best practice’ approach- a peer-reviewed document, a doctoral thesis, that could be circulated to all schools considering the development of an ASD unit. Consequently, I drafted a research proposal and found that such a thesis was indeed viable. However, a number of factors conspired to create a certain sense of unease in presenting a ‘nuts and bolts’ approach to ASD programme development. These factors

included the fact that, firstly, ‘models’ are widely open to interpretation, particularly when such ‘knowledge’ enters the public domain. As Woods (1986: 96) notes “*physical models are less than perfect, and those of social life, with all its intricacies, inconsistencies and contradictions are even less so.*” Secondly, the programme could only claim to have been empirically ‘tested’ (particularly through observation) over a 3 year cycle, the ‘junior programme’. Thus the model was incomplete. A further 3 years of exploratory programme development would be required to address the crucial issue of transition from school to society within the context of a subsequent ‘senior programme’. Thirdly, the model could not claim in any way to be perfect or ‘watertight’. For instance, while it did succeed in including children who were labelled as ‘low-functioning’- those with very limited speech- it did not include any children who would be classified as ‘non-verbal’, thus the model could not be said to be truly representative of the full spectrum of Pervasive Developmental Disorders. Autistic individuals with the most severe forms of communicative impairments- individuals as old as 18 years- were still locally attending special schools dedicated to the more established methods of TEACCH (‘Treatment and Education of Autistic and related Communication-Handicapped Children’- see Schopler & Mesibov, 1984) and ABA (Applied Behavioural Analysis’- see Lovaas, 2003).

Thus, I was facing something of a dilemma. ‘Packaging’ what I had developed would fall well short of satisfying what I wanted my doctorate to accomplish- namely, the production of a thesis that would have the scope to inspire as much as to inform, one that would capture the imagination whilst simultaneously maintaining its academic integrity. Fortunately, in April 2008, the thesis, in a sense, ‘presented itself’ to me within the context of a meeting with the parents of one of the first pupils to enter my programme, Sean Cronin. At the meeting John and Noreen Cronin expressed their thanks to me that Sean was doing so well in school. He was partaking in conversation with members of my staff and I (albeit they were limited conversations), he was performing particularly well in out-of-school recreational activities, and he was happy to go to school every day. These were ‘new milestones’ for Sean, John and Noreen explained to me, but none of them were transferring across to his home environment. Their wish, they further explained, was to learn how to encourage Sean to interact with them, their other two sons, and with wider members of his family. Could I, they asked, offer some advice as to how a long-term programme may be developed for Sean that may enrich his quality of life?

The issue of transition beyond schooling

This question, this challenge, intrigued me. Grappling with it would challenge me to open myself up to entirely uncharted territory. It would challenge me to take a much more holistic view of education, to face head on the assertion of a parent of an autistic child- interviewed by Wittemeyer *et al* (2011: 30)- that “*education is redundant unless it leads you somewhere.*” Exploring the concept of ‘quality of life’ as it relates to Sean would allow me to explore, in multiple contexts beyond the school walls, issues relating to transitions beyond schooling for young people with autism.

Parsons *et al* (2009), in an report commissioned by the National Council for Special Education² in relation to autism provision, found that only 10% of articles focused on the needs of post-primary-aged children and young people (12–16 years) with autism, and that where there was research involving older students, it tended to focus upon those with Asperger Syndrome or ‘High Functioning Autism’, concluding that “*very little is known about what constitutes appropriate provision, or an effective intervention, for older children and young people on the autism spectrum*” (Parsons *et al*, 2011: 60) and made “*a strong recommendation for further work to be undertaken regarding the needs of adolescents and adults with autism*” (ibid: 57). There has been virtually no ‘outcome research’ (Wing, 2002) conducted with older individuals with autism, resulting as Parsons *et al* (2011: 47) put it, “*limited evidence regarding the needs of older children as well as consideration of educational provision more widely, including the effects of type of setting, as distinct from a specific type of intervention or learning approach.*”

Significantly, the Parsons *et al* (2011: 57) study found “*no evidence identified through the empirical strand that looked at transitions beyond schooling.*” In particular, the study reported an important gap relating to a lack of research on “*settings [which] address explicitly questions of social validity and longer-term outcomes for children, young people and their families*” (ibid: 61) and recommended the “*carrying out [of] robust, meaningful and ethically appropriate research in the real-world contexts of children and families’ lives, both at home and beyond*” (ibid: 59). This had implications for the fieldwork design which

² The Parsons *et al* (2009) study was an NCSE commissioned review of the international literature on best practice in educational provision for children and young people on the autism spectrum in order to inform Ireland’s policy development.

would be carried out across a multiplicity of settings, both in Sean's home and the wider community, with the continual input and involvement of Sean's parents and his siblings.

The decision to adopt a single case study design

Adopting a single case study design seemed most appropriate and 'sat well' with me both as a teacher and a researcher; in the sense that I was a teacher wishing to do something positive for the family of one of my pupils who sought my advice and assistance, and that I was a researcher wishing to make a meaningful contribution to knowledge in the fields of autism studies and educational research. The success of the ASD programme which I had coordinated was not attributable to any 'magic formula' in designing a form of educational provision; rather, it was entirely due to the dynamism of the children who really characterised the programme. It is interesting to note that nowadays, in delivering autism-specific teacher training workshops, I always return to one key point. That is in developing the ASD programme over 3 years, several mistakes were made on the part of various stakeholders, myself included, through the process of trial and error; all stakeholders- with the exception of one- the kids themselves. *"The only stakeholders", I constantly reiterate, "who never dropped the ball, were the kids. On the contrary, it was more of a case of the kids teaching us, than us teaching the kids."*

The first implication of this, as it applies to this thesis, was the realisation that in the conceptualisation, development, and evaluation of any programme in education- be it special education or otherwise- the fundamental 'units of analysis' should be nothing less than the children or young people themselves. Should a school wish to present a particular programme to the wider educational community as something worth seriously considering implementing elsewhere, it should do so- this study contends- by celebrating the uniqueness and diversity of the individual children and/or young people who underpin the programme in question; a bottom-up 'human-inductive' approach as opposed to a reductive top-down appraisal of the merits of one particular teaching method, or 'model of provision' over another.

The second implication was the realisation of the enormous scope of what I could potentially learn about the meaning of 'quality of life' in autism when the inquiry was intensely focused upon *one person*. This would entail a dual exploration of, and investigation into, both autism and personhood on a 'micro' level. As I have mentioned, everything that I have learned about

disability and SEN that holds true meaning for me, I have learned through my experiences of individual children, teenagers and adults across the spectrum of first, second and third level education. Yet, I had never ‘studied’ one person in a particularly focused way. Considering that I had been fortunate enough to learn a great deal from people when the relationship I shared with them was that of the normal pupil-teacher/pupil-tutor variety, imagine what may be potentially discovered when the relationship was widened and further developed with a view to exploring the phenomenon of ‘quality of life’ as it relates to one person. What could the findings suggest for other teenagers with autism, their teachers, their families and for how we ‘teach’ young people with autism?

Obviously, ‘quality of life’ is an enormously broad concept, complicated by a number of factors. Firstly, as Wittmeyer *et al* (2011: 9-32) note, “*There is a lack of a clear definition of what good adult outcomes should be... [for a person with autism]...what is a good pattern of outcomes for one person might be completely different for another.*” Yet on the other hand, they further note, “*it is only by defining what good adult outcomes should look like, that we begin planning educational provision to achieve those goals*” (ibid: 11). Exploring the concept of ‘quality of life’ as it relates to Sean was a constantly exploratory and ever-shifting process- before, during and after the 31 day period of fieldwork activities (which will be outlined in chapter 2). Ultimately, the study concludes (in chapter 5) that enhancing ‘quality of life’ for young people with autism may be achieved most optimally by working *with* those young people and their families, in helping them to create a vision for their own future by tapping into what *motivates* them on a human level, by drawing upon the power of their individuality and personality, as opposed to assessing and ‘measuring’ them against sets of fixed criteria which relate exclusively to their perceived functional abilities and disabilities.

A participatory, ‘capability’ approach in the production of ‘relational’ knowledge

Children and adolescents with all forms of special educational needs, in both special and mainstream educational settings, are the recipients of powerful professional categories (Barton, 1998). Their world, Clough & Barton (1995) maintain, is set about with a particularly forceful categorical thinking which envelopes their identities. Diagnostic labels, Swain (2000) further contends, create particular pathologies, which are assumed to be an embodied part of individual identity, create individuals as subjects of professional intervention, and play a role in the maintenance of professional power.

The ways in which concepts of autism are constituted, and in which they emerge as particular types of problems in certain fields of knowledge, produce what we understand as ‘knowledge’ of autism. The human subject is in turn rendered knowable as an ‘object’ of these forms of knowledge which constitute what is desirable to be done with people, how they are to be understood, related to and organised. Autism, this study contests, is not a condition about which professionals can claim to un-problematically amass absolute knowledge; rather it is- taking a Foucauldian perspective- a discursively constituted object. As Peters (1995) maintains, disability is a socially constructed and historically mediated process, its underpinning ‘knowledge’ having been constructed, as Barton (1998) adds, based upon a firm distinction between researchers and ‘the researched’; upon the belief that it is researchers alone who have specialist knowledge and expertise, and that it is they alone who should decide what paths research studies should take.

In contrast, a guiding principle of the case study presented in this thesis relates to *learning from* my case study participant, Sean, through a process of sharing control in an attempt to address Barton’s (1998) question in relation to what ‘academic integrity’ may amount to in such a context. This is in keeping with Peter’s (1995: 34) contention that “*accepted knowledge in relation to disability can only be challenged by stepping outside of traditional approaches to research which have reproduced ‘given’ knowledge of disability as a medical-psychological product of innate individual traits, in a move towards creating the possibility of a new construction of knowledge in the field of education for special needs students.*” Essentially, as St. Pierre (1997: 176) puts it, “*If data are the foundation on which knowledge rests, [then] it is important to trouble the common-sense understanding of that signifier, in postfoundational research that aims to produce different knowledge, and to produce knowledge differently.*”

In chapter 2, I outline the psychiatric classification system of Pervasive Developmental Disorders (popularly referred to as ASDs) as outlined in the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (American Psychiatric Association, 1994) and the *International Classification of Diseases, 10th edition* (World Health Organisation, 1993). Essentially, in chapter 2, I make the point that the classification of ASDs is of little value to educators in informing educational practice and argue that, on the contrary, the classification system of ASDs has served to polarise educational provision for people with autism, and indeed marginalise those labelled as falling into what are often regarded as the ‘low

functioning' categories of ASD such as 'childhood autism' and 'atypical autism'. As Jim Sinclair (who has autism) candidly puts it, *"the misconception that any given autistic person has an across-the-board 'functioning level' means that people considered 'low functioning' are denied opportunities for access and self-determination because it's presumed that they're unable to benefit from those opportunities; while people considered 'high functioning' are denied supports that would enable them to pursue opportunities, because it's presumed that they're able to function without needing those supports"* (Sinclair, 2011: 1).

Moving beyond the inflexible notion of a 'functioning level', exploring 'what autism is'- in how it relates to individual people- is best achieved, this study contends, through a single case study design. Cohen *et al* (2011: 222) define a case study as *"an investigation into a specific instance or phenomenon in its real-life context."* *"Case study research"*, they add, *"recognises the contribution that a genuine creative encounter can make to new forms of understanding education, regard different ways of seeing as new ways of knowing....with an overriding interest in people"* (ibid: 290). The case study presented in this study is concerned with exploring Sean's 'human condition' as well as his 'autistic condition'- understanding him in the totality of his life. The study concludes, in chapter 5, that the 'autistic self' is only one aspect of Sean's self, that there are many other- indeed a *multiplicity*- of 'selves' that come together to characterise Sean's unique personality, what makes him 'him'. Uncovering those 'selves' was strongly attributable to adopting a single case study design because, as Sacks (1985: x) notes, *"only by restoring the subject to the centre [of inquiry] do we have a 'who' as well as a 'what'...a real person in relation to the physical."*

The study of autism, this study contends, should not limit itself to 'autism itself' but further consider how individual people with autism *react* and *accommodate* to the condition. As Sacks (1985: 6) puts it, *"there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for and to preserve its identity, however strange the means may be: and to study or influence these, no less than the primary insult to the nervous system, is an essential part of our roles."* Thus qualitative studies of autism, as I will discuss in more detail in chapter 3, may be enriched by a 'capability approach' which as Terzi (2005 b: 451) explains *"sees disability as inherently relational."* While perspectives emphasising individual limitations rely upon the use of classificatory systems, based mainly upon medical or psychological categories, *"the capability approach distinguishes between functionings and capabilities"* (Terzi, 2005 a: 204).

A single case study design, this study contends, is particularly well suited to studying the phenomenon of autism, precisely due to such a design's ability to deal with the *specific* and the *particular*. If anything could be said for 'what autism is', it is that it is 'multiple things'. It affects different people in entirely different ways; some positive and some negative. In my own experience I have never met two autistic people who are even remotely similar. What characterises people with autism is their uniqueness; their own particular interests and abilities, their highly individualised preferences for self-expression and the diversity of their personalities. Capturing and exploring individual difference is the 'stuff' of the single case study positioned within a 'capability approach' because, as Terzi (2005 a: 206) notes, "*capabilities are context-sensitive*", and as Cohen *et al* (2011: 291-294) further add, "*the single case study design can separate the significant few from the insignificant many instances of behaviour. Significance rather than frequency is a hallmark of case studies, offering the researcher an insight into the real dynamics of situations and people.*"

Rationale for a single case study approach

Yin (1984) identifies 3 types of case study in terms of their intended outcomes; (1) exploratory case studies (which serve as a pilot to other studies or research questions), (2) descriptive case studies (providing narrative accounts of events), and (3) explanatory case studies (those which test theories). The case study presented in this thesis is perhaps best described as an 'exploratory single case study', which I will return to in chapter 3. However, in addition to being exploratory, this case study is likewise descriptive and, to some extent, explanatory. Chapter 4- the case study itself- is essentially a 'story' in which descriptive analysis (writing as a form of analysis in its own right) is intended to convey the central findings of the research. As Cohen *et al* (2011: 290) stress "*it is important in case studies for events and situations to be allowed to speak for themselves, rather than to be largely interpreted, evaluated or judged by the researcher.*" Case studies should be, as Nisbet & Watts (1984: 79) maintain, "*immediately intelligible.*"

This 'immediacy of intelligibility' in case study research leads us into an important aim of the case study presented in this thesis relating to- namely- its accessibility to as wide an audience as possible. "*The power of the case study approach lies*", according to Miller & Kantrov (1998: 1), "*in the discussion or experience that is created around the case....a well crafted case is like an evocative photograph that captures a subject, invites multiple interpretations,*

and is rich enough to sustain repeated encounters.” The “*knowledge produced*” from a case study should, according to Merriam (1988: 20), “*be judged on the extent to which it is understandable and applicable.*” While clearly the primary objective of this thesis- as a piece of work- is to fulfil a set of academic criteria, to be reviewed by my peers as a credible contribution to knowledge in the field of autism studies, this does not necessarily mean- in my view- that it should be limited to an academic audience. As Cohen *et al* (2011: 292) point out, “*the case study is capable of serving multiple audiences.... it makes the research process itself accessible.*” Since the completion of an earlier version of this thesis in December 2011, I presented the case study to a group of 7 parents who have children with autism (5-17 years) throughout a six-week workshop in March-April 2012. Upon the completion of the workshop I distributed a questionnaire for no other reason than to collect feedback that would allow me to improve the workshop for the next group of parents. On one of the questionnaires a parent had noted “*Your thesis gives a voice to my child.*” It was perhaps the most humbling comment I had ever received from a parent who I had known for such a relatively short period of time, but one that I took very seriously.

People can relate to *stories* on a profoundly human level that perhaps no other art form can offer. Stories inspire, they offer hope; stories are ‘exemplars’ of possibility. “*The power to describe*”, Sacks (1985: x-6) maintains, “*which was so common to the great nineteenth-century neurologists and psychiatrists is almost gone now. It must be revived...publish such histories even if they are just sketches. It is a realm of great wonder.*” While, as Miller & Kantrov (1988: 2) concede, “*a case study may be a relatively short text*”, case studies may, they further note, “*prompt conversation and reflection on a set of issues that are framed through a narrative.*” Case studies presented through the medium of narrative are among the most accessible forms of academic writing. As Denzin & Lincoln (2008: 7-8) maintain “*narrative texts are dialogical texts. They presume an active audience. They create spaces for give-and-take between reader and writer [in which] readers and audiences are invited to explore competing visions of the context, to become immersed in and merge with new realities to comprehend.*”

Yin (1984) finally characterises ‘explanatory’ case studies as those which ‘test theories’. In the forthcoming chapter I discuss a number of theories which have dominated the literature relating to autism across the spheres of cognitive psychology and neuropsychology over the past 3 decades. It is important to clarify at this point that this study holds the deepest respect

for the dominant theories which are discussed, as well as for the academics who developed them- some of the most accomplished academics in the field of autism research; researchers such as Francesca Happé, Uta Frith and Simon Baron-Cohen. It is crucially important to clarify that I regard my approach to studying autism as only *one approach* in a multidisciplinary effort to uncover truths in relation to an enormously multi-faceted phenomenon. As a researcher I attempt to bring my own set of strengths to the table. As previously mentioned I have always been drawn to people. During my short career I have been able to develop my skills in working with people, refine them and use them for constructive purposes, as well as developing a passion for writing people's stories. Thus, I am almost inevitably drawn towards qualitative research- since that is where my skill set rests most comfortably and is consequently the sphere within which I am more likely to make something approaching a worthwhile contribution.

While this study does not set out to 'test' dominant theories, theories such as 'systemizing theory' and 'theory of mind' for instance, it does attempt to contribute to new understandings and interpretations of them. This study attempts, ultimately, to demonstrate how the understandings underpinning certain cognitive and neuropsychological theories of autism may be extended and enriched by qualitative research, rather than being bypassed or simply dismissed upon the basis that they do not 'fit' with the qualitative framework. This study suggests that the naturalistic/interpretative paradigms in autism research can contribute to, and indeed compliment, objectivist/positivistic paradigms and their findings. The ongoing positivistic/naturalistic debate in social-scientific research is well encapsulated by Cohen *et al* (2011) who explain that "*positivism claims that science provides us with the clearest possible idea of knowledge. Where positivism is less successful, however, is in its application to the study of human behaviour where the immense complexity of human nature and the elusive and intangible quality of social phenomena contrast strikingly with the order and regularity of the natural world.*" What this study suggests however is that 'scientific' and more 'naturally derived' forms of knowledge need not necessarily be mutually exclusive. Whilst they are different forms of knowledge which in a sense resist *direct* 'intersection', this does not mean that they are not capable of a wider *complimentary* 'connection' in autism research, if only because autism, as a phenomenon, is far greater in scope than any one methodological approach or paradigm. A key theme of the literature review in the following chapter is that whilst it is important to be aware of the physical and cognitive/psychological difficulties that co-exist with autism, in approaching the much broader question of 'what autism is'- as it

relates to and affects the lives of individual people- necessitates a qualitative, humanistic approach that does not see knowledge of autism as ‘fixed’, but something that is constantly open to reinterpretation depending upon how we *interpret* the ‘deficits’ associated with the condition and our own responses to them.

Thus, in chapter 5 in relation to ‘theory of mind’ (Baron-Cohen *et al*, 1985) and ‘systemising theory’ (Baron-Cohen & Ring, 1994) for instance, I do not argue for a rejection of those scientific theories, but rather for a reinterpretation of the former and an extension of the latter. ‘Theory of mind’ or ‘mentalising’ deficit- the difficulty that many people with autism experience in ‘putting ones self in the shoes of another’- seeing events from others’ perspectives- is an often inescapable, unchangeable reality inherent within the autistic condition. It leads to the ‘directness’ that we associate with autistic people- a directness that is unchangeable and may be largely unalterable by any degree of ‘social skills training’. Yet what *is* subject to change is how that directness is understood, interpreted and responded to. While one person may interpret undiluted directness as ‘rudeness’, another may interpret it as ‘honesty’. Thus while ‘Theory of Mind’ may always remain static as a cognitive construct or neurological condition, its interpretation may shift in light of experientially-based studies with individual people with autism that illustrate that ‘mentalising’/’Theory of Mind’ deficit does not reflect a domain-like deficit in empathy, but may in fact be seen as reflective- as this study attempts to illustrate- of the very opposite; ultra-sensitivity to the situations, and indeed the feelings, of others.

Similarly, an extension of ‘systemising theory’ does not reject the scientifically-based finding that people with autism construct predictable systems in order to bring some sense of order to a world reduced to chaos. This study acknowledges and deeply respects the fact that children with autism may line up toys, for instance, for no other reason that *the line itself is predictable and thus creates a sense of consistency and safety*. Wendy Lawson (who has autism) relates an experience in which she was asked by the mother of an autistic 12 year old boy as to why he screamed when the railing he had been following and holding onto came to an end. “*I tried to explain*” Lawson (1998: 142) described, “*the concept of familiarity and change, of gaining a sense of security and of self, as perceived through the railings. I gain these emotions by touching inanimate objects or something with continuity like railings, wearing my hat and feeling the definition on my head, or by being held firmly by my friend.*” Yet ‘systems’, this study contends, can be extended. The systems (that I will describe in

chapter 4) that Sean ingeniously developed to internalise, experiment with, and retain invented characters in memory in his ‘world of autism’ were *exactly the same systems* that he applied to the internalisation, connection, and retention of newly evolving ‘real world’ friendships during the course of our fieldwork together.

Setting the research parameters and initial exploratory research questions

According to Merriam (1988: 7) “*descriptive case studies are usually inductive in nature....it is impossible to identify all the important variables ahead of time.*” Needless to say, exploring the phenomenon of ‘quality of life’ as it relates to Sean was a highly exploratory process in which emergent and continually evolving aims and points of inquiry unexpectedly revealed themselves throughout the course of the 2 month period of fieldwork, and indeed well beyond the period of fieldwork itself; into the very final stages of data analysis.

The period of fieldwork was itself characterised by a number of important turning points, brought about by new, unique insights into the *person* Sean Cronin, in particular his power to perform tasks previously considered to be outside of his range of capability when placed in control of his own actions, as well as his all-consuming drive to help those less fortunate than himself when *real control* was factored into his life for the first time, leading to an *intensity of purpose* which ultimately drew the fieldwork towards its somewhat dramatic conclusion with his ascent of Ireland’s highest mountain, ‘Carrauntoohil’, to raise money for the Vesnova Children’s Orphanage in Belarus. When and how the aims of the study changed and shifted are detailed throughout chapters 3 and 4. However, it is important to clarify that the aims of the study- at its outset- were not random but were rather positioned within a set of 3 key points of contention which frame the ‘special education debate’.

The first point of contention- a question so basic to the very idea of special education itself- is what precisely is a disability? The question here is not one of proper identification of various disabilities, but rather of a more fundamental nature concerning the ontological assumptions underlying opposing understandings of the very nature of disability. Ontology addresses the nature of being, as well as the basic categories of being and their relations. Fundamentally, it asks what constitutes the *identity* of an object or person.

The second issue centres around debates in relation to preferred research methodologies and which methodologies lead to the most valuable and/or ‘useful knowledge’ in special education. This debate mirrors the dispute over the use of empiricist/realist versus interpretivist/hermeneutical research in the broader field of education. It is fundamentally grounded in issues of epistemology- the nature and scope of knowledge. Epistemology asks, 1) what is adequate knowledge and, 2) how is adequate knowledge acquired.

The third point of contention, and perhaps the most discordant of all, is the conflict over ‘place’, or where students understood to have disabilities or ‘special educational needs’ (SEN) should receive their education. This dispute, referred to as the ‘inclusion debate’, in many ways subsumes the preceding ones and might be seen as the ultimate issue facing special education (Gallagher, 2004).

In setting the initial points of inquiry of the case study within the parameters of these 3 key points of contention I was effectively asking:

1. What is ‘autism’ as it relates to Sean and what are the implications of autism for his ‘quality of life’? In other words, ontologically speaking, where do the boundaries lie between his ‘autistic condition’ and his ‘human condition’ and what are the implications of this in acquiring a deeper understanding of him and his identity?
2. What methodologies and methods of data collection are most ‘useful’ and ethically appropriate in exploring this question?
3. How can these questions be explored across various contexts or ‘sites of experience’?

Key turning points in the study and shifting ‘lenses of inquiry’

As chapter 3 will fully outline, the 2 month period of fieldwork consisted of 31 days of fieldwork in which Sean was involved in a number of different activities. 12 of the 31 days consisted of activities between Sean and I, while 19 of the days involved 17 additional project participants including his brothers, his parents, his SNA, a classmate, his ASD community support workers, as well as key activity leaders in activities including horse riding, go-karting, yachting, Tae Kwon Do and mountaineering. The fact that activities involving additional participants considerably outweighed one-to-one activities was not, however, set in stone upon the outset of the fieldwork.

The one-to-one activities between Sean and I were initially intended to explore how Sean operates within the ‘world of narrative’. It is worth, at this point, drawing attention to appendix G, ‘*Sean’s internal world of pretence and the Aron narratives*’ which, drawing upon his artwork in particular, provides insights into what might be termed ‘Sean’s world’, his ‘autistic world’ - a uniquely fascinating world composed of a number invented characters and protagonists that bear striking resemblances to the alternative worlds created by autistic individuals who have written of their own ‘private worlds’. Many of Sean’s invented characters which are often hybrids and different ‘versions’ of characters he comes across in movies, cartoons, comics and video games; characters such as ‘Aron’ and ‘Ciara’ (see appendix G) may be likened, for instance to ‘Carol’ and ‘Willie’ - the ‘imaginary friends’ created by Donna Williams. “*Carol and Willie*”, Williams (1994: 10-12) explains “*were my ‘more real’ inner family, the characters I had created and through whom I had lived two-thirds of my past twenty-five years....Willie was the first member of my self-contained, untouchable mobile family.....Carol came along a year and a half after Willie. She took possession of the object that was my living-corpse body and shared it with ‘the world’ in exchange for acceptance...my face had glowed with the discovery of a friend with whom I could feel safe and understood.*”

The reason for applying particular focus to Sean’s ‘narrative processing’ lay in my assumption (which I still hold to be true) that in order to explore what ‘quality of life’ means from the perspective of a person with autism, it is necessary to enter into and explore both the person’s ‘autistic world’ as well as the ‘other’ world- the world that surrounds it (this assumption is further discussed in relation to autism-specific teaching methods in chapter 2). However, I quickly discovered not long into the period of fieldwork, that I was discovering more about how Sean processes narratives in entirely unplanned for everyday situations than I had anticipated, and that his openness to revealing more and more about his inner world increased dramatically when he was involved in new, stimulating activities during which he was developing new relationships and friendships with others. Interestingly, the vast majority of what I discovered in relation to Sean’s ‘world of autism’ occurred during our car journeys to and from the sites of our activities; times when Sean was stimulated and excited.

More importantly, as the fieldwork progressed, my exploration in relation to how Sean processes narratives internally (in the cognitive sense) was overtaken by a more important, albeit unexpected, lens of inquiry; namely how Sean’s love of narrative may be explored in

different social contexts and in different forms (such as live dramatic and musical performances). Ultimately, I found that it was by *connecting* Sean's love of narrative; including imaginary characters, that were in fact very deeply 'linked' to his own multiple senses of self- to his social world (by utilising narrative as a 'bridge' between the autistic and social worlds) that I managed to gain a more global understanding of him, and gain important insights into what 'quality of life' may mean from his perspective.

Like my exploration of Sean's 'autistic world' shifted, so too did my exploration of his 'social world'. It could be argued that Sean's social world was 'constructed' throughout the course of the fieldwork, and to a large degree it was. It was not fully representative of his 'normal' day-to-day life, but this was largely dictated by the ethics of the project; to open him up to new, stimulating experiences. Initially, it was Sean's engagement and performance in a number of new activities *themselves* that I was focusing upon. On a basic level I was trying to find out which activities he would enjoy most, and by identifying these, explore how his continuing involvement in these activities may contribute to his long-term quality of life. So for instance, in my first interview (with yachting instructor Brendan Cronin, day 5-14/06/2010- see appendix H) my line of questioning related strongly to how Sean may develop boating as a long-term hobby. In addition, my field notes for days 1 (pleasure cruise in Kinsale harbour) and 5 (yachting in Crosshaven harbour) revealed a preoccupation with how boating may stimulate Sean in a sensory/vestibular way due to the movement of the boat. However I very quickly realised that it was not primarily the activities themselves, but rather the human-relational dynamics that underpinned them that really stimulated Sean. In addition I realised that when Sean was granted *control* over his own actions, his performance soared. Thus, from day 5 onwards, the lens of inquiry was as much pointed towards the human dynamics at play during social activities, more so in fact than the activities themselves, leading ultimately to a wider investigation into the internalisation and maintenance of friendships in Sean's life.

As chapter 3 will describe in more depth, there were also *ethical aims* which heavily underpinned the project design, incorporating methods of data collection, the nature of my engagement with those methods, as well as dissemination of the findings of the research; both during and following the 2 month period of field work. Of foremost importance was that the period of fieldwork would be a positive experience for Sean. Rather, the project was entirely focused upon Sean's wellbeing- the project was designed as much to be 'for him' as it was

intended to be ‘about him’. I would like to think that ethics fundamentally dictated the project, in that its purpose was 1) to bring enjoyment to Sean throughout the 2 month period over which it was conducted, as well as, 2) bringing about some findings that may be considered by Sean’s immediate family, his wider family, his teachers, and his SNAs, that they may be invited to consider in order to *empower them* to develop educationally-based, home-based, and community-based programmes for Sean which, I hope, may contribute to Sean’s quality of life into the future.

Positionality as teacher, friend, and researcher

In relation to the issue of researcher ‘positionality’ in social research, Cousin (2010: 17) contends that “*researcher reflexivity is best shaped by a fluid, negotiated view of positional space.*” The scope for shifting positionalities, or perhaps even *evolving* positionalities is, this study maintains, one of the most profound ‘gifts’ that may be bestowed upon any social researcher. In chapter 3, I discuss some more and less traditional concepts of ‘validity’ and ‘reliability’ in social research, but ultimately adhere to the view of Cohen *et al* (2011: 219-222) that “*when the researcher becomes, as it were, the ‘human instrument’ of the research... trustworthiness and its components replace more convenient views of reliability and validity.*” There has been no greater honour in my professional career to date, than to be invited so warmly into the Cronin home; into the lives of John, Noreen, Conor, Ciaran and Sean. To be extended the opportunity for the “*open and honest sharing of experiences*” (Van Niekerk & Savin-Baden, 2010: 34), the necessary trust developed that, as I discuss in chapter 5, allowed us to *collectively* raise the bar of opportunity and possibility for Sean, based upon a concrete foundation of nothing less than friendship and mutual investment in Sean.

Perhaps one of the most positive outcomes of this study has been the development of what I am confident will be life-long friendships between the Cronin family and I, between the Cronin family and my own family, between Sean and I, and between Sean and many of the project participants. Friendship, this study maintains, far from being something to be feared as verging on ‘bias’ or crossing the boundaries of professional practice (either as this relates to a researcher or a teacher), is something, rather, to be wholeheartedly embraced when and wherever it emerges in the course of a study, or indeed when it is invited into a study (by the researcher inviting his/her own trusted friends and/or family to participate in the study). Ultimately, this study attempts to add to the debate relating to ‘good adult outcomes’ for

young people with autism (see Wittemeyer *et al*, 2011) by emphasising both the validity and power of different ‘forms’ of friendships to deeply enrich quality of life for those on the autistic spectrum, as well as indeed, the lives of those whom they befriend.

CHAPTER 2- LITERATURE REVIEW

Introduction

The following literature review attempts to explore the concept of ‘what autism is’ from a number of multifaceted perspectives. Ultimately the chapter argues that while autism is certainly a condition that is bio-genic in origin, the true ‘condition’ of autism- as it relates to individual people- is determined more by the accommodations that those individuals make to their difficulties. While it is important, as this chapter maintains and explores, to be aware of the difficulties that people with autism encounter (which are explored across the paradigms of clinical medicine, cognitive psychology, neuropsychology and neurology), it is likewise important to be aware of how people with autism skilfully accommodate to their difficulties and that what are referred to in psychiatry as a ‘restricted range of interests’ are better understood as talents and ‘unique interests’. This has implications for how educators design autism-specific teaching programmes (which are further discussed in the course of the chapter), as well as for parents, siblings, friends and relatives of people with autism. It is often a lack of understanding- of both the difficulties and strengths that people with autism possess- that works against the development of ‘good adult outcomes’ for people with autism, an issue that is central to this study (and is discussed in depth in chapter 5). For this reason the concluding sections of this chapter explore not only ‘what autism is’ from a bio-genic perspective, but also ‘what autism feels like’ from the perspectives of a number of authors who have autism.

Autism as a cultural phenomenon

‘Autism’, or the more modern term ‘ASD’ (Autistic Spectrum Disorder), is a phenomenon of relatively recent origin in the field of psychiatry. ‘Autism’ (meaning ‘aloneness’) was not first described (by Leo Kanner) until 1943. Until the publication of DSM-III in 1980 the word ‘autistic’ had been nothing more than a descriptive term used in the diagnosis of Childhood Schizophrenia (in DSM II, 1968). Asperger’s Syndrome was not described by Hans Asperger until 1980. Nor was Asperger’s Syndrome made an official diagnosis until 1994 with the publication of DSM-IV.

Yet autism clearly existed long before 1943. While it falls well outside the scope of this literature review to offer a detailed account of people in history who most likely had what we now call ‘autism’ it is interesting to make the observation that how people with autism were perceived and regarded within their varying cultures throughout the course of history may have been entirely different from how we have tended to perceive and ‘treat’ autism in the west since the advent of modern psychological/psychiatric practice, and in particular since the emergence of the system of psychiatric classifications that came with the advent of the ‘Diagnostic and Statistical Manual of Mental Disorders’ published by the American Psychiatric Association between 1952 (DSM-I) and 1994 (DSM-IV).³

Uta Frith (1989), in examining records from 16th - 19th century Russia, has discovered fascinating accounts of the so-called ‘blessed fools of Russia’, children and adults, who as Frith describes were preoccupied with repetitive behaviours and who needed to be confined, so they didn’t wander away, and had seizures.⁴ Frith explains that they were often mute, and if not mute they were echolalic (repeating back words or sentences verbatim). What is most interesting to note in relation to Frith’s account of the ‘Blessed fools of Russia’ is that far from being cast off from society as ‘fools’ (in terms of the modern connotation of the word) the ‘blessed fools’, or the ‘village idiots’, were said to embody ‘blessed innocence in the eyes of God’. For instance, one such ‘blessed fool’, Pelagija Serebrenikova, who lived in 16th century Russia was considered to be a ‘blessed and holy fool’ and *because* she was deemed to be ‘blessed’, she was not expected to conform to the standard conventions of society. In chapter 5, I will argue that autism may be best understood as a number of ‘conditions’ that are attributable not only to ‘autism’ itself, but- far more importantly- how others choose to understand autism and consequently engage with those on the autism spectrum.

Such an historical-social perspective upon ‘what autism is’ stands out in marked contrast to how contemporary psychiatry and modern day society have conceptualised, defined and ‘treated’ autism. Yet there are many contemporary non-western cultures that perceive autism as being something far more powerful and emotive than merely an ‘intellectual disability’. In some such non-western societies, the symptoms of autism are not thought to be abnormal as much as they are *divine or spiritual*. These include the so called ‘marvellous children’ of

³ In the interim period DSM-II was published in 1968, followed by DSM-III in 1980, followed by a revised edition of DSM-III (DSM-III-R) which was published in 1987.

⁴ The fact that many of the ‘blessed fools’ had seizures, Frith pointed out, suggests that they had autism rather than schizophrenia, since the frequency of seizures in schizophrenia is relatively low.

Senegal, called ‘Nit-ku-bon’, and the Navajo Indian children with autism in the American southwest, who are seen simply as ‘perpetual children’. Grinker (2009) has documented many conversations he has had with women in rural India who regarded their autistic children as resembling the gods and the saints. For instance Seung-Mee took comfort in her church’s conviction that her daughter, Soo-Yong, was more pure than others, and closer to God. Additionally, in a modern day congregation in rural Maryland, USA, children with autism are, in fact, worshipped as the body of Christ while, in Israel, the ultra orthodox Jewish community view a child with autism as being a vessel containing the untold words of Christ.

Yet this is not to suggest that all non-western cultures value people with autism primarily as spiritual beings. There are sheer horror stories, such as that related to Grinker in his conversation with a young Peruvian school teacher, Lily Mayo, who in 1975, visited a church hospital outside Lima where children and adults with autism were kept in cages. Over the adult cages the priests had hung a sign that read, ‘No Te Acerques Por Que Muerdo’ (Beware, I bite). “*The villagers and the priests*”, Lily explained, “*believed the children were either possessed by the devil or being punished for the sins of their parents.*” (Grinker, 2009: 9). Tragically, in the yards of Peruvian state institutions, she witnessed naked boys being brutally tied to poles as punishment for biting themselves or banging their heads. Thus autism is really two ‘conditions’. It is all the symptoms that we are familiar with, plus the stigma and exclusion that society attaches to it, a branding; a way that society judges us for transgressing the boundaries of what is considered to be acceptable and normal. “*It is culture*”, Grinker (2009: 14-16) contends, “*that sees something as abnormal or wrong, names it, and does something about it... Illnesses may be biological but they are never simply biological.*”

Classifications of Autistic Spectrum Disorders

Although autism is commonly accepted as being a neurobiological disorder, no biological test as yet exists for autism. One cannot examine autism under a microscope nor diagnose it in a lab test. The only way that autism can be diagnosed is through an examination of an individual’s behaviour.⁵ Yet there is little agreement, even within a single culture, as to what exactly autism is, or how it should be treated.

⁵ The most common standardised assessment instruments for the diagnosis of autism in children and adolescents are the ADI (*Autism Diagnostic Interview*) (see Couteur *et al*, 1989), which is a two-hour caregiver interview, and the ADOS (*Autism Diagnostic Observational Schedule*) (see Lord *et al*, 1989) which consists of a series of

Current criteria for the modern day diagnosis of autism are set out in the *International Classification of Diseases*, 10th revision, Geneva (ICD-10, 1993), published by the World Health Organisation, as well as the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV, 1994), published by the American Psychiatric Association. These criteria (or the ‘Triad of Impairment’ as it is commonly termed) are, namely, qualitative impairments in social communication, social interaction, and social imagination, with a restricted range of interests and often stereotyped repetitive behaviours and mannerisms. The 7 differential diagnosis of ASD that appear ICD-10⁶ are outlined in appendix B.

Common ASD classifications in Ireland

Within the Irish psycho-educational context the three most recognised and diagnosed forms of ‘ASDs’ are ‘Classical Autism’, ‘Asperger’s syndrome’ and ‘Pervasive Developmental Disorder, not otherwise specified’ (PDD-NOS). The first is typically equated with what is termed ‘low functioning’ autism (implying a co-existing cognitive/language delay in addition to autistic behaviours) and the second with ‘high-functioning’ autism (implying intelligence/verbal IQ within the normal/above average range but with some of the behaviours typical of autism). The third category, PDD-NOS- in reality- places a child squarely in the middle of ‘no man’s land’ of psychiatric classification.⁷ Appendix A (Sean’s developmental and early educational history) describes how on December 18th 1998 Sean was diagnosed as having ‘low-functioning autism in the severe range’. The only prognosis,

play-based tasks given to the child. Such diagnostic procedures are often preceded by the use of screening instruments such as the M-CHAT (*Modified Checklist for Autism in Toddlers*) (see Robins *et al*, 2001) and the Q-CHAT (*Quantitative Checklist for Autism in Toddlers*) (see Allison *et al*, 2008).

⁶ The DSM-IV (1994) classification system of Pervasive Developmental Disorders is broadly in keeping with the ICD-10 (1993) system although there are two notable differences. In DSM-IV (1994) *Atypical autism* is included within the ‘pervasive developmental disorders, not otherwise specified’ category and *Childhood autism* is classified as a category of ‘*Autistic Disorder*’.

⁷ In 1980 the PDDs included five categories. The first was ‘Infantile Autism’, or ‘Kanner’s syndrome’ with onset before 30 months. Diagnostic criteria included pervasive lack of responsiveness to other people, gross deficits in language development, peculiar speech patterns (if speech was present) such as immediate and delayed echolalia, metaphorical language and pronominal reversal. The second category was ‘Child Onset Pervasive Development Disorder’ to cover the small number of cases of autism that developed after the age of 30 months. The first and second diagnoses were then broken down further into 2 additional categories, ‘Infantile Autism Residual State’ and ‘Childhood Onset PDD Residual State’. Residual state diagnoses were used when the features that fulfilled the criteria for that disorder in the patient had diminished significantly over time by either number or severity. Finally, there was an additional diagnostic category, the catchall, ‘Atypical Pervasive Developmental Disorder’, to describe the children who had problems and delays in multiple areas but not enough problems to warrant a specific diagnosis. Seven years later, in 1987, when the revision of the DSM-III was published as DSM-III-R, that category would become the infamously ambiguous ‘Pervasive Developmental Disorder Not Otherwise Specified’ (including Atypical Autism) category.

based upon such a diagnosis, was institutional care. This was the apparent ‘reality’ - the ‘end’ that Sean’s parents were asked to accept before their son had even reached his fourth birthday. This study fundamentally rejects the idea of a ‘functioning level’ in autism and argues strongly that *people with autism function at the level to which we permit them to function.*

Medical investigations into the condition of autism

Internationally, prevalence rates for autism range from between 1 in 100 to 1 in 167 children (Parsons *et al*, 2011). Nationally, the incidence of autism in Ireland is currently estimated at being 1 in every 166 people⁸ (Irish Autism Action, 2010). It is commonly accepted that autism has a genetic basis. Multiple genes are likely to be involved, and linkage studies have identified possible candidate genes on chromosomes 2q, 7q, 16p, and 19p (Baird *et al*, 2003). However, no specific candidate genes have yet emerged. Nonetheless, genetic studies have established that autism is strongly heritable. Family studies have shown that first degree relatives of people with autism have a raised risk of autism compared to population baseline levels (Folstein & Rutter, 1988) and twin studies implicate a genetic aetiology even more persuasively.⁹ Autism may, however, also be caused by etiological factors which lead to abnormalities in the development of brain structures and processes. Such abnormalities may be caused, for instance, by prenatal complications such as rubella infection, untreated metabolic disorders such as phenylketonuria, anticonvulsants taken in pregnancy, localised lesions as in tuberous sclerosis, and postnatal infections such as encephalitis (Baird *et al*, 2003).

Anatomical studies have investigated brain structures and processes in deceased autistic subjects. Bauman and Kemper (1985), for instance, in a study using whole brain serial sections, reported increased cell packing, reduced cell size and reduced connections in many parts of the limbic systems of autistic donors. The authors suggested that since this picture resembles what is typically seen during an early stage of normal brain maturation, their findings may indicate a curtailment of development in older children with autism. In addition,

⁸ There are currently no figures for the prevalence of autism in Ireland, although an Irish prevalence study is currently underway in Trinity College, Dublin (Droney, 2009).

⁹ The concordance rate for autism among monozygotic twins has been found to be as high as 60%, whilst the concordance rate among dizygotic twins has been found to be no higher than the sib risk rate (Bolton & Rutter, 1990). Bailey *et al* (1995) have suggested that autism is likely to be a complex genetic trait involving more than one gene locus (estimated at between three and seven genes).

they found abnormalities in the cerebellum and inferior olive of the brainstems of the cadavers.

Clinical studies have explored the neurologically relevant signs of autism including toe walking, nystagmus (involuntary movements of the pupils of the eyes), motor posturing, hypotonia (low muscle tone), muscle spasticity, abnormal persistence of infantile reflexes, and epilepsy. (Table 3 in the following chapter sets out the clinical difficulties that are specific to Sean) Within the field of autism studies such behaviours are commonly investigated within the clinical framework of what is known as ‘Sensory Integration Disorder’. ‘Sensory integration’ refers to the co-ordination and regulation of the *external senses* (sight, sound, vision, tactile & olfactory) and the *internal senses* (the vestibular and proprioceptive senses). The vestibular sense dictates the movement of the head in relation to gravity, whilst the proprioceptive sense is concerned with muscle tone and the sensations generated inside the body which mark where the parts of the body are in relation to each other (Miller, 2006). As chapter 4 will describe, difficulties with proprioception presented perhaps the greatest physical challenge to Sean in a number of activities throughout the period of fieldwork.

It is believed that the underlying nature of sensory integration difficulties involve the cerebellum, limbic systems and cortical mechanisms of the brain (Droney, 2011). Sensory integration difficulties occur when the child experiences difficulty in regulating the sensations that operate within any of these seven senses.¹⁰ The brain simply cannot process the endless stream of information being thrown at it, and becomes, as Ayres (1972) metaphorically puts it, ‘stuck in an endless rush-hour traffic jam’. This leads, as Droney (2011: 64) describes, to everything being “*too loud, too bright, too fast or too tight.*” This, Harrison & Hare (2004), suggest may be responsible for many of the classical features of autistic behaviour such as the twirling of fingers in front of the eyes, smelling others, wrist flapping, twirling around, hypo/hypersensitivity to temperature, and unusual vocalizations.

Clinical speech and language studies have investigated a number of communication disorders that often co-exist with autism, including that of ‘semantic-pragmatic disorder’, a condition in which speech is fluent and grammatically correct but wherein there is a serious deficit in the

¹⁰ Ashburner *et al* (2008) have contended that children with autism need speech to be 2-3.5 decibels louder than typically developing children to enable comprehension in the presence of background noise.

understanding of speech (Wing, 2002). Semantic-pragmatic disorder often gives rise to immediate echolalia (repeating all or part of what has just been said) and delayed echolalia (repeating statements/chunks of language that the child heard sometime in the past) (Stengel, 1964). It is thought that in the case of echolalia, while the child maybe able hold a phrase in short-term auditory memory (immediate echolalia) or long-term auditory memory (delayed echolalia) sufficiently long enough to reproduce it, the comprehension of language is affected by an underlying central auditory processing disorder (Charlop, 1983). However, Siegel (2003: 211) maintains that it is important to acknowledge that echolalia may be a “*partial self-accommodation*” made on the child’s part in which he/she may be attempting to communicate to the listener that he/she is “*trying to respond*”, something which is explored throughout the course of chapter 4.

Biochemical studies have formed a further medical research paradigm. Such studies have investigated altered levels of neurotransmitters (chemicals involved in carrying an electrochemical signal from one neuron to another, enabling the signal to jump across the synapse or gap between neurons) in autistic subjects. A biochemical study conducted by Anderson *et al* (1990), for instance, found that the levels of the neurotransmitter serotonin (chemically known as 5-hydroxytryptamine, or 5-HT) were elevated in blood samples taken from people with autism. Serotonin is a monoamine neurotransmitter, synthesized in the serotonergic neurons in the central nervous system, as well as in the gastrointestinal tract which plays an important role in regulating anger, aggression, mood, sleep and appetite (Baron-Cohen, 2008). In addition, reduced levels of the neurotransmitter GABA (gamma-amino butyric acid) have been observed in autistic individuals. GABA serves an inhibitory role in the brain and it is possible that reduced levels of GABA may leave a person with autism in an over-responsive, over-stimulated state (which may be said to characterise Sean’s ‘pretending’ which will be described in chapter 4) due to too much neuronal firing (Baron-Cohen, 2008).

Cognitive and neuropsychological theories of autism

Cognitive theories

The rise of cognitive accounts of autism can be traced back to Hermelin & O’Connor (1970) who first contrasted autism with other forms of intellectual and sensory disability (blind and

deaf) and concluded that there could be specific impairments in autism over and above the general lowering of IQ attendant on brain damage, and that neither lowered IQ nor a peripheral input problem could explain the specific pattern of impairments in autism. In the following section I will outline 3 dominant cognitive-psychological theories that have emerged within the field of autism studies. This will be followed by a brief overview of 4 neuropsychological theories of autism which, likewise, have had a significant influence upon how autism has been conceptualised.

Cognitive-psychological theory 1: Systemising theory

There is, I would argue, a great deal of insight underpinning the view of Baron-Cohen & Ring (1994) that children with autism seek out *patterns*, or *systems*, in an attempt to bring meaning, predictability and order to an often chaotic world. They define ‘systemizing’ as the drive to analyse or construct systems in order to identify the rules that govern that system; in order to predict how the variables within that system may behave in the future. Baron-Cohen (2008) went on to identify 14 forms of autistic systemizing which may be summarised as follows:

- Sensory (eg, sniffing people, tapping surfaces, insisting on same foods),
 - Motoric (eg, spinning, rocking),
 - Collectable (eg, flags, stickers, making lists),
 - Numerical (eg, calendars, dates, rapid calculation of prime numbers),
 - Motion-based (watching things spinning),
 - Spatial (eg, obsession with routes, studying maps, developing techniques),
 - Environmental, (eg, lining up objects in an invariant order, memorizing names of objects),
 - Social (eg, timetables, playing the same games, learning social hierarchies),
 - Natural (eg, classifying plants and animals),
 - Mechanical (eg, building lego models),
 - Auditory/vocal (eg, echoing sounds, imitating accents),
 - Action-sequential (eg, watching the same video over and over again),
 - Musical (eg, listening to the same song over and over again, analysing musical structure),
 - Moral (telling tales, insisting that others follow social rules)
- (Baron-Cohen, 2008).

‘Systemising Theory’ is an alluring theory on many levels. Yet the shortcomings of this theory I respectfully suggest, are 1) that it conceptualises systemizing as being an entirely mechanical process divorced from emotional/social influence, 2) that it presents each of the 14 forms of systemizing as being ‘closed systems’ unto themselves and does not investigate how they might actually link up with external influences and 3), as a result, falls short of offering a conceptual framework within which one may extend the principles of systemizing to those of social life; a phenomenon that is explored and discussed throughout chapters 4 and 5.

Cognitive-psychological theory 2: Empathising-Systemising theory

An extension of Baron-Cohen’s systemizing theory, ‘Empathising-Systemising theory’ (Baron-Cohen, 2008), seeks to explain the social and communication deficits in autism with reference to delays and deficits in empathy (E), whilst explaining areas of strength with reference to intact or superior skills in systemizing (S).¹¹ According to this theory, it is the discrepancy between ‘E’ and ‘S’ that determines a person’s level of autism. I find this theory rather difficult to accept since it could be argued that this theory is essentially suggesting that the more proficient an autistic person is in creating closed systems, the less likely he/she is to care about other people (an assumption that my case study refutes).¹²

Cognitive-psychological theory 3: ‘Theory of mind’

One of the most influential cognitive theories of autism has been that of ‘theory of mind’ (sometimes referred to as ‘mentalising’, ‘mindreading’ or ‘mindsight’ deficit); the theory that people with autism are unable to represent the mental states, thoughts and feelings of others and are consequently unable to understand or predict the behaviour of others in terms of those

¹¹ According to Baron-Cohen (2008) mindreading is just the cognitive component of empathy (*cognitive empathy*). The second component of empathy is the ‘response element’, having an appropriate emotional reaction to another person’s thoughts and feelings. This is referred to as the affective component of empathy (*affective empathy*).

¹² A third, slight further extension, of this theory is referred to as the ‘Extreme Male Brain’ theory of autism (Baron-Cohen, 1999). This theory postulates that the male brain is superior to that of the female brain when it comes to ‘systems thinking’, whilst the female brain is superior to that of the males within the realms of empathy and understanding the thoughts and feelings of others. The contention is that people with autism may have, what is termed, ‘extreme hypermale’ brains, on the opposite end of a spectrum where one would find the ‘extreme hyperfemale’ brain, which this theory suggests is ‘systemblind’. Again, I find this theory difficult to accept due to the fact that, like ‘empathising-systematising’ theory, it assumes that people with autism are fundamentally deficient in the capacity for human empathy.

states. Put more simply, ‘theory of mind’ is the ability to put oneself into somebody else’s shoes.¹³ Difficulties in comprehending the mental states of others may be said to be one of Sean’s most pervasive ‘social difficulties’, many examples of which will be referred to throughout the course of chapter 4. Leslie (1987) has proposed that the developmental origins of ‘mindreading’ may lie in the child’s capacity for pretence which normally starts emerging between 18 and 24 months of age. According to Leslie, pretence is the ‘crucible’ for a ‘theory of mind’. Meltzoff & Gopnik (1993) have further suggested that for the typically developing child, imitation is effectively a ‘tutorial in social understanding’, and that lack of early imitation skills severely restricts a child’s subsequent capacity for social insight.

There is some additional evidence that a child’s capacity to mentalise can be traced to even earlier developmental origins. A study carried out by Sigman *et al* (1986) reported severe deficits in *joint attention* in children with autism. Joint attention refers to those behaviours produced by the child which involve monitoring or directing the target of attention of another person, so as to coordinate the child’s own attention with that of somebody else’s (Bruner, 1983). Such behaviours include the pointing gesture, gaze monitoring and showing gestures which are normally well developed by 14 months of age in typically developing children (Scaife & Bruner, 1975; Butterworth, 1991).

Baron-Cohen (1999) has argued that an inability to ‘mentalise’ is, in itself, an insufficient global explanation of the wide range of social impairments which appear in autism. He suggests that in order to gain a more comprehensive understanding of those social impairments, it is necessary to move beyond the broad ‘Theory of Mind’ level of analysis, towards a consideration of a wider range of experimental cognitive studies. The findings of a cross section of such studies are summarised and presented in appendix C.

¹³ Wimmer and Perner (1983) devised the well-known ‘theory of mind’ or ‘false-belief’ test. A child was presented with a short story involving one character being absent when an object is moved and therefore does not know that the object is in a new location. The child being tested is asked where the character thinks the object is. Wimmer and Perner found that normally developing four year olds correctly inferred that the character would think that the object was where the character left it. Baron-Cohen *et al* (1985) subsequently found that a sample of children with autism (who had additional mild degrees of global cognitive delay) failed this test by indicating that the character would look for the object where it actually was. Baron-Cohen (1999) notes that they appeared to disregard the critical fact that, by virtue of being absent during the scene, the character’s mental state would necessarily be different from the child’s own mental state. The results produced by control group of children with Down Syndrome (who also had mild degrees of global cognitive delay), whereby they passed the test as easily as normally developing children, led the authors to conclude that children with autism may be specifically impaired in the development of a theory of mind (Baron-Cohen *et al*, 1985).

Neuropsychological theories

The neuropsychological paradigm in autism research, which emerged strongly in the early 1980's, has attempted to link the biological and psychological levels of analysis in autism research by mapping relationships between brain structures and the psychological and behavioural functions that they are assumed to serve. Francesca Happé and Uta Frith have been steady proponents of what they term 'the integrative role of neuropsychology' in attempting to find 'bridges' between the autistic brain and autistic behaviour (Happé & Frith, 1989).

Neuropsychological theory 1: Neuro-anatomical investigations into 'Theory of Mind'

While the 'Theory of Mind' account of autism originated as a cognitive theory, a number of subsequent investigations into the brain basis of 'theory of mind' have influenced its emergence as a neuropsychological theory. Such investigations have sought to identify which regions of the brain play a role in the task of 'mindreading'. In the 1980s 4 regions of the brain were identified as possibly contributing to this process',¹⁴ which in 1994, Baron-Cohen & Ring suggested may form parts of a *neural circuit* supporting theory of mind processing. By 2008, six further regions of the brain had been identified as playing a role in 'mentalising' tasks, constituting what Baron-Cohen (2008) has termed the 'social brain'. In the typically developing brain each of these regions were found to be activated during 'mindreading' activities, and were found to be under active in the autistic brain. These regions of the brain are the fusiform face area, the temporal-parietal junction, the superior temporal gyrus, the inferior frontal gyrus, the anterior cingulate cortex and the posterior cingulate cortex (Baron-Cohen, 2008).

¹⁴ -Functional imaging using SPECT (Single-Photon Emission Computed Tomography) scans revealed that the *right orbito-frontal cortex* is active when individuals are thinking about mental state terms (Baron-Cohen *et al*, 1994.)

-Functional imaging using PET (Positron Emission Tomography) scans revealed that the *left medial frontal cortex* is active when subjects are drawing inferences about thoughts (Fletcher *et al*, 1995).

-An investigation using the brain of a monkey found that the *superior temporal sulcus* plays a role in the monitoring of gaze-direction (Perret *et al*, 1985).

-Brothers (1990) reviewed evidence suggesting that the *amygdala* contains cells sensitive to gaze and facial expressions of mental states.

Neuropsychological theory 2: Executive dysfunction theory

Duncan (1995) defines ‘executive function’ as an umbrella term covering a wide array of higher cognitive processes; the ability to disengage from context, inhibition of inappropriate responses, planning sequences of willed actions, staying on task, monitoring performance, using feedback, and shifting attentional set. The issue of maintaining ‘attention’ features heavily throughout chapters 4 and 5, in particular how we may help people with autism to maintain their attention upon tasks and people. Neuropsychological research into ‘executive function deficit’ in autism has been largely based upon the hypothesis that there is a link between frontal lobe damage, executive function and autism. Hughes *et al* (1993), for instance, have argued that ‘mentalising deficit’ in autism can be explained with reference to a broad, domain-general deficit in executive control processes, most likely due to frontal lobe damage.

The ‘Executive Dysfunction’ theory of autism was originally proposed by Norman & Shallice in 1980. They contended that without a fully functioning ‘supervisory attentional system’, impaired by dysfunction within the frontal lobes, children with autism were essentially *controlled by their environment*, such that such children simply ‘responded’ to cues which elicited behaviour allowing no scope for inference or any other form of abstract thought.¹⁵ However, Duncan (1995) has argued that ‘Executive Dysfunction’ theory fails to take account of the intact and superior skills often displayed by people with autism. He suggests that a spiky IQ discrepancy is a case in point; block design which is so often an observed strength in the testing of individuals with autism is considered a good test of ‘fluid’ intelligence, which in turn relies on executive abilities. Baron-Cohen (1999) further adds that executive dysfunction occurs in many other clinical disorders¹⁶ implying that in itself an impairment in executive function cannot explain autism.

¹⁵ Without a supervisory attentional system, Norman & Shallice (1980) suggested that ‘action schemas’ or ‘motor programmes’ *contend between themselves* for execution within a system known as the ‘contention scheduling system’ which they contended is broadly a basal-ganglia function, whilst the supervisory attentional system is basically a frontal lobe function.

¹⁶ These include Schizophrenia, Obsessive-Compulsive Disorder, Tourette Syndrome, Attention Deficit with Hyperactivity Disorder, Parkinson’s Disease, Frontal Lobe Syndrome, Phenylketonuria and Mental Handicap (Happé & Frith, 1996; Baron-Cohen, 1999).

Neuropsychological theory 3: Weak Central Coherence theory

Drawing upon Gestalt psychology, ‘Weak Central Coherence’ theory posits that autism may be characterised by a failure of the ‘built-in propensity’ in normal human information processing to form coherence over as wide a range of stimuli as possible, and to generalise over as wide a range of contexts as possible (Frith, 1989). This failure, it is argued, stems from a processing style in which there is a tendency to perceive and construe complex stimuli as a disparate collection of parts rather than coherent, integrative and meaningful wholes.

Happé (1999), in reviewing evidence of brain overgrowth in autism, has presented an interesting neuropsychological hypothesis for ‘weak central coherence’ which relates to the disruption of programmed cell death and neural pruning in autistic brain development. Happé (1999) asserts that an excess of neurons in autistic subjects may support piecemeal and exemplar-based processing and learning, but to the detriment of the development of more holistic processing strategies such as would be required, for example, to process verbal information for its ‘gist’ rather than in a literal manner. Neurologically speaking, this theory posits that in autism there is short-range overconnectivity (more nerve cells or neurons making lots of local connections in the brain) but long-range underconnectivity (fewer neurons making connections between more distant brain areas).

According to Happé & Frith (1996) ‘Weak Central Coherence’ theory surpasses other theories of autism upon the basis that it does not present a ‘deficit account’ of autistic information processing, and goes some way towards explaining the ‘splinter skills’ observed in some people with autism. They suggest that the noticeably uneven pattern of intellectual abilities encompassing both assets and deficits in performance, the repetitive phenomena of stereotypes and preservative behaviour, as well as the core impairments in social interaction and communication, are more intelligibly viewed as manifestations of a more general dysfunction in the capacity for coherence. Such behaviours, they argue, are manifestations of a weak ‘drive’ for central coherence that ranges from the integration of lower-level perceptual inputs to the derivation of higher-level meaning.¹⁷ However, while the ‘Weak

¹⁷ ‘Weak Central Coherence’ theory has been examined with a range of experimental materials noted for their gestalt-inducing qualities, where weak central coherence would be expected to confer a significant task *advantage* for people with autism. For example, Shah & Frith (1983) posited that superior performance by autistic individuals, relative to controls, on the block design subtest of the WISC (Wechsler Intelligence Scale for Children) (Wechsler, 2004) was due to a greater ability to segment the whole design into its component

Central Coherence' theory of autism seeks to transcend the strictly deficit conclusions espoused by 'Executive Dysfunction' theory, it could be argued that there is a fine line between what constitutes 'ability' and 'deficit' under this theory. An 'ability' to segment designs into their component parts could as easily be described a 'disability' to engage in the wider context. Based upon the findings of chapter 4, chapter 5 will argue strongly that 'weak central coherence' may be better understood as an ability to apply uncompromising focus upon the particular and to perceive what Sacks (1985) terms 'the elemental'.

Neuropsychological theory 4: Mirror Neuron theory

Finally, investigations underpinning the 'Mirror Neuron' theory of autism have revealed that in the typical brain certain regions are active not only when the person themselves performs an action but also when that person observes another person performing the same action.¹⁸ Neuro-imaging studies have found that when children with autism make facial expressions of emotion, or look at someone else's facial expression of emotion, they show less activity in the pars opercularis region of the brain. The pars opercularis is a part of the inferior frontal gyrus which is thought to be part of a neurological 'mirror system' (Baron-Cohen, 2008). This, it has been suggested, could go some way towards explaining 'mentalising' deficits in autism.¹⁹

Taken collectively, the findings of cognitively-based research studies (particularly 'Theory of Mind' and 'Systemising Theory', as well as those studies summarised in appendix C) provide important insights into some of the psychological difficulties which may manifest themselves

parts. Similarly, Happé (1996) found that individuals with autism were less susceptible than controls to standard visual illusions that depend upon surrounding context for their effect. Campbell *et al* (1995) meanwhile found that children with autism performed equally well at judging the identity of familiar faces in photographs whether they were given the whole face or just part of the face. Finally, using the children's version of the Embedded Figures Test (Witkin *et al*, 1971), Shah & Frith (1983) found that their 'low functioning' autistic participants were significantly superior to both mentally handicapped and normal controls in their ability to find hidden shapes. Jolliffe & Baron-Cohen (1997) further extended these findings by showing that 'high-functioning' individuals with autism and with Asperger's syndrome were superior to normal controls on the adult version of the EFT.

¹⁸ The idea that the same mirror neurons fire when one performs an action, as when one watches another performing the same action was described somewhat 'less neurologically' by Boal, as early back as 1979 as '*metaxis*'- doing something and watching oneself doing it at the same time. The power of performance, Boal (1979) concludes is its 'double edge'; offering a metaphorical device for exploring a range of perspectives, and analytical potential for understanding why people think and behave as they do.

¹⁹ Goleman (2007) has further suggested that mirror neurons may be crucial for 'mindsight', citing an fMRI imaging study conducted with a group of young autistic and non-autistic teenagers which revealed that the autistic group showed a deficiency in prefrontal cortex mirror neuron activity while reading and imitating facial expressions.

as sources of fear, frustration and anger for individuals with autism. Potential difficulties, such as confusing thoughts with reality, misunderstanding not only the mental states of others but also the language used to describe them, experiencing difficulty in comprehending when another is pretending or being deceptive, as well as the perception that life's events almost always happen *to* them; 'planes fly high *because* I'm not afraid of heights' (Grandin, 2006), are important, in my view, to at least be aware of in working with individuals with autism.

The same may be said in relation to neuropsychological theories of autism (in particular 'Weak Central Coherence Theory'). As I will allude to throughout chapters 4 and 5, it is not that the dominant theories of autism should be rejected, simply upon the basis that they are deficit-orientated theories, but rather that they may be reframed and reinterpreted in order to make their findings and insights as constructive as possible in working with people with autism. The findings of the theories outlined above have been important in their own right, and within their particular fields of inquiry. Yet, how educators *professionally engage* with those findings (which will be described and discussed throughout chapters 4 and 5 in relation to Sean) is ultimately, this study argues, what dictates the value and ethical credibility of those theories in educational practice. However, of all of the dominant theories of autism outlined above, none deal in any depth with the memory difficulties that so often co-exist with autism, an issue that features strongly in the case study presented in this thesis. For this reason it is necessary to temporarily depart from literature dealing specifically with autism and consider, more generally, the nature of human memory.

Autism and human memory

Introduction

Difficulties in retaining other people in memory is, as chapter 4 will explore, another of Sean's more pronounced difficulties. Memory may be defined as the brain's ability to encode, store and retrieve thoughts and sensory experiences (Cowen, 1997). *Short-term memory* is the component of memory that we use to store small amounts of information (verbal and non-verbal) for short periods of time, up to approximately 30 to 45 seconds. The dominant theoretical concept of working memory, put forward by Baddeley (2003), suggests that a 'limited capacity system', which temporarily maintains and stores information, supports human thought processes by providing an interface between perception, long-term

memory and actions; actions which Miyake & Shah (1999) add may include language comprehension or production, problem solving, decision making, and other forms of thought.

‘Immediate echolalia’ (which often characterises Sean’s speech) may be due to an over-reliance on short-term auditory memory as an attempted compensation for difficulties with long-term auditory memory. This takes place within what is termed the ‘phonological loop’ of short-term/working auditory memory. The phonological loop is the working memory’s means of holding onto- and holding together- the spoken word. It works by repeating or ‘rehearsing’ relevant words, numbers or syllables to avoid the auditory memory fading away to nothing (Gibb, 2007). When the phonological loop of an individual is impaired, long-term and short-term auditory memory may be likewise impaired. In extreme cases (such as immediate echolalia) the person may be relying upon an even shorter form of auditory memory known as ‘echoic memory’ which has a working capacity of approximately 4 seconds (Kane & Engle, 2000).

The second component of working memory (relating to short-term visual memory) is what is referred to as the ‘visuospatial sketchpad’ (Baddeley, 2003). The most immediate form of visual memory (which lasts for approximately one tenth of a second) is known as ‘iconic memory’. Because the brain is capable of perceiving much more than it is capable of recalling, iconic memory allows a person to *perceive* a mass of visual information but not to *recall* it. Traditionally, it has been found that in the cases of people with autism, visual memory is significantly stronger than auditory memory. Grandin (2006) argues that acute visual memory, ‘thinking in pictures’ as she terms it, is a particular skill of using visualisation as a means of concretising events, concepts and philosophical considerations, that is an outstanding characteristic of many autistic people. Less attention has been paid however to the inherent strength of auditory memory (or what I will later refer to in chapter 4 as ‘phonographic’ memory).

Encoding and storing memories

For a memory to be transferred from short-term memory into *long-term memory*, it must first be *encoded*. This means that it must be *associated, in a meaningful way, with information already present*. During this process, which takes place largely during sleep, neurones undergo potentially permanent change. Our memories are founded upon what is known as

‘synaptic plasticity’- the varying of the strength of signals between two neurones, across a synapse. This means that when an axon of cell A is near enough to excite an axon of cell B, and repeatedly or persistently takes part in firing it, *actual metabolic change* takes place in one or both cells such that A’s efficiency, as one of the cells firing B, is increased (Stanton *et al*, 2005). In other words, if one cell consistently causes another to fire, the pair develop an ever-strengthening *connection*.

Committing individual items of information to memory, then, involves creating *new networks of strengthened neuronal connections*. When the brain recalls a memory it causes a *specific network* of neuronal connections to re-fire in the brain once again, allowing the associated information to enter into consciousness and, finally, into long-term memory (Gibb, 2007). Long-term memory is thus a complex web of interconnections wherein the more associations that the brain can make between memories, the more successfully they can be stored and retrieved. When we come to recall a memory, we navigate this web, exploring a specific ‘web’ of connections to reach what we are looking for. After continued practice a critical threshold is eventually reached and the neurones involved in the process *undergo permanent change*. This change involves a number of the cell’s proteins becoming activated, one of which is called CREB (Cyclic Adenosine Monophosphate Response Element Binding Protein). Once activated, CREB journeys from its peripheral location within a neurone towards the nucleus, the home of the cell’s DNA. Once there, it binds with other nuclear proteins, and to the DNA itself, resulting in specific genes (small, functional stretches of DNA) within the neurone’s genetic code being ‘switched on’. This cascade of new gene activation brings about the formation of new proteins with a new set of tasks resulting in the emergence of new synaptic connections between partnering neurones (Gibb, 2007).

Forgetting and the perception of time

But why do we forget? Or, more importantly, what helps us to remember? ‘Retroactive Interference Theory’ suggests that when we forget information is not randomly *lost* from the brain, but rather *other* information, be it old or new, can prevent a person from being able to *retrieve* a particular memory that they may be searching for (Baddeley & Dale, 1966). One of the main reasons for this may be due to *similarities* between certain memories which make them difficult to distinguish from one another. In other circumstances, older memories affect one’s ability to create new ones- a phenomenon known as *proactive interference* (Kane &

Engel, 2000). But essentially, forgetting, which usually occurs within an hour or so after learning or experiencing the thing being forgotten, occurs because, *no associations can be made with existing memories*. Remembering is about *forming connections*. “*One thing seems clear*”, Gibb (2007: 75) maintains, “*the more a memory is recalled, the more likely it, and its associations, will be remembered.*” Chapters 4 and 5 will explore in depth how people may be retained in memory through the power of association, and how those memories can be retained even further through what will be discussed as the ‘performance text’.

Temporal perception and the ordering of experience

When we recall a memory, we can usually remember not just what happened, but also *when* it happened, and roughly how long the event being recalled lasted for. In other words, our memory system is intimately interconnected with our brain’s ability to *perceive a time continuum* (Baddeley & Scott, 1971). It would not be an over-statement to suggest that Sean prior to, and at times during, the study seemed entirely ‘lost in time’. Our perception of time, known as ‘temporal perception’ is also crucial to our physical movements (swinging a tennis racquet, for instance, to hit a moving ball, requires extremely accurate calculations about the time it will take both the racquet and the ball to reach the point of impact). Imaging studies have revealed that our sense of timing can be affected by the cerebellum, the basal ganglia and the right parietal cortex. This makes sense of the altered perception of time experienced by sufferers of Parkinson’s disease which affects the basal ganglia, as well as that of some right-hemisphere stroke sufferers with damage to the right parietal cortex (Gibb 2007). Interestingly however, even without any form of neurological damage, our perception of the speed of time passing is not fixed. Thus, for instance, when we are busy time seems to pass by quickly, but when there is little or nothing to occupy our mind’s attention, the brain becomes acutely *aware of time itself* which stretches out before us, much like a mountain with no discernable summit. Helping Sean to manage and regulate time is a key feature of the case study presented in chapter 4, the conclusion being that granting people with autism *control* over time parameters may be the key to improving temporal perception.

The ‘divided’ brain

In 2009, Dr. Iain McGilchrist published a landmark book, “*The Master and his Emissary- the Divided Brain and the Making of the Western World*”; a thesis that won the Scientific and Medical Network book prize 2009. While McGilchrist’s thesis is not directly related to the topic of autism, in the following section I will outline why I believe that many of McGilchrist’s neurological insights may open up new conceptual frameworks within which the condition of autism may be conceptualised beyond the fixed assumptions which sometimes underpin empiricist/realist constructions of knowledge, towards a more interpretivist/hermeneutical engagement with the phenomenon of autism that does not see knowledge as fixed, but as something that is constantly shifting and subject to change.

McGilchrist’s (2009) thesis is based upon the view that the twin hemispheres of the modern human brain can largely be seen as 2 highly autonomous systems. An evolutionary history of anatomy would suggest that ‘things come together’. Things do not, in evolution, normally grow further and further apart. Yet curiously, both hemispheres of the brain are *not drawn towards each other*, rather *they are more inclined to ignore each other*. This is because the estimated 300-800 million fibres which form the Corpus callosum, which connects both hemispheres of the brain serve to actually *inhibit* either hemisphere from interfering with the other. And this is because the aforementioned neurotransmitter GABA, which is present in the nerve cells of the Corpus callosum, serves an *inhibitory* rather than an *excitatory* function (McGilchrist, 2009).

The ‘divided brain’ and autism studies

So we have a ‘divided brain’. What makes this significant for autism studies? After all McGilchrist’s thesis is ‘not about autism’. It is significant, I suggest nonetheless, because when one examines the functions of the left hand side hemisphere of the brain, one may see- reflected back to them- almost all of the ‘classical features’ of autism. The left hand side hemisphere prefers rigidity, structure, order and predictability. It favours the ‘mechanical.’ It doesn’t like change. Neither does it sit comfortably with unpredictability, especially the unpredictability of social information. Similarly, it favours information which can be slotted into *systems* that facilitate *order and predictability*. The right hand side hemisphere, in

contrast, relishes social information. Unlike its left hand side counterpart it loves coherence, connectedness and flow. And it thrives upon emotion.

Yet, in spite of the inhibitory role of the Corpus callosum, this study suggests that while people with autism may be primarily ‘left-brained’, they may potentially make tripedent moves across the neurological divide towards the more naturalistic, connected world of the right hemisphere. Oliver Sacks has been a firm and steady proponent of what he has termed ‘the give and take of the brain.’ Basically, this view contends that the human brain, especially that of a child, has a tremendous ability to transfer functions, or to compensate by developing existing functions, when part of it has been damaged (Sacks, 1985). ‘Synaptic plasticity’ as I have previously referred to, is essentially the stronger the younger we are.

Sacks (2008) describes a paper published by Geschwind & Galaburda (1987) which reported that in left hemispherectomies, drastic procedures in which the entire left hemisphere (the so-called ‘speaking hemisphere’) of the brain is removed, may be followed by the development of language functions in the right hemispheres of young children. In addition, there is evidence which further suggests that in those born blind or early blinded, the massive visual cortex, far from remaining functionless, is reallocated to other sensory inputs, especially hearing and touch, and becomes specialised for the processing of these (Pascual-Leone, 2003).

If the left hemisphere is the hemisphere of ‘*what*’, the right hemisphere, with its preoccupation with context, the relational aspects of experience, emotion and the nuances of expression, could be said to be the hemisphere of ‘*how*’. But what then are the implications for teaching children with autism? The key implication, I suggest, is this; *we should strive to respect the ‘left brain preferences’ - but celebrate ‘right brain accomplishments’ - of pupils with autism.* ‘Left brain preferences’ are those which, I suggest, the individual clings onto for a sense of *safety*. Yet the right hand side hemisphere, somewhat metaphorically, represents the ‘land of opportunity.’

The coherence of the right hemisphere

It could be argued that the autistic preference for sameness may be explained through the left hemisphere’s preference for existing, reliable knowledge, something that as chapter 4 will describe, heavily characterises Sean’s day-to-day persona. The left hemisphere, the ‘autistic’

hemisphere if you like, *positively prefers what it already knows* and, thus, *prioritises the expected*. Thus, when faced with a problem, a person with autism may take the *single solution* that seems to best fit what *they already know* and *latch onto it*, consequently struggling to cope whenever initial assumptions need to be revised. The right hemisphere is much more capable of a frame shift than the left. It can present *an array of possible solutions* to a problem, which remain live while alternatives are explored.

There is more white matter in the right hemisphere which facilitates rapid transfer of information *across regions* while the left hemisphere prioritises local communication, transfer of information *within regions*. Thus, while the left hemisphere is the hemisphere of *systems*, the right hemisphere is the hemisphere of *connections*. The right hemisphere understands from indirect contextual clues, whereas the left hemisphere will identify by labels rather than through context. It is the right hemisphere's capacity for holistic processing that allows, for instance, the individual to recognise people whom they have met previously, as well as places they have visited previously. So while the left hemisphere can understand emotional display, it looks not at the eyes but at the mouth as a reference point for emotional display. It is the right hemisphere alone that seems to be capable of understanding the subtle information that comes from the eyes. We can, I suggest, gain a deeper understanding of 'weak central coherence' by considering that the left hemisphere may cling onto decontextualised items of information- the information that it already knows- as *truths*, reliable truths, dependable truths. Yet they are *unconnected* truths like a thousand unconnected 'dots' floating about in space.

The 'divided brain' and the nature of attention

In the human brain the left hemisphere is responsible for *narrow focused attention*, while the right hemisphere is responsible for *breadth and flexibility of attention* ('global attention'). The left hemisphere attends to things abstracted from context and broken into parts, while the right hemisphere attends to things *connected*- in whole and in context. In addition, the right hemisphere is largely responsible for the *sustaining of attention*. In fact, people who suffer right hemisphere lesions (especially right frontal lobe lesions) become grossly impaired in vigilance and sustained attention, and exhibit perceptuomotor slowing- diminished alertness with very frequent lapses of attention (McGilchrist, 2009). Therefore, the question presents itself; how can we help individuals with autism to sustain their levels of attention? The

answer, this study will suggest, is that we must create *contexts* within which they *want* to do this. One way of doing this, as I explore in my case study, is to tap into what is significant for such individuals on a *personal and emotional level*. What is of most crucial importance in helping people with autism to achieve sustained levels of attention, as I will argue in chapter 5, is to grant them more *control* over what it is they are attending to.

Emotion and ‘betweenness’ are, this study contends, the prerequisites to real and meaningful human connection and communication, as well as to the retention of events embodying these, in memory. In all forms of emotional perception, regardless of the type of emotion, and in most forms of expression, the right hemisphere is dominant. The right hemisphere is deeply attracted to, and given life by, the relationship- the ‘betweenness’- that exists with the other. This is because the right hemisphere is more intimately connected than the left hemisphere with the limbic system, an ancient subcortical system that is involved in the experience of emotions of all kinds. It is the right frontotemporal cortex that exerts inhibitory control over emotional arousal and the right super temporal sulcus that is involved in the recognition of facial emotion (McGilchrist, 2009).²⁰ By tapping into the *emotional aspects of what motivates* an individual with autism, this study suggests, it is possible to entice the person towards the connective, holistic power of the right hemisphere.

Widening ‘concepts of communication’ in autism studies

The left hemisphere of the human brain has traditionally been associated with human speech, and by association with, ‘human communication.’²¹ However, it is not actually true that language resides only within the left hemisphere. While it is true that the syntax and vocabulary of language are housed within the left hemisphere, it is the right hemisphere that houses our higher linguistic functions (Panksepp & Bernatsky, 2002). Dunbar (2004) has

²⁰ For instance, it is the area around the fusiform gyrus of the right hemisphere that is dominant for the unconscious reading of emotional shifts that are expressed in minute facial changes which are mirrored and synchronously matched by the observer’s right hemisphere within 300-400 milliseconds, at levels beneath awareness (McGilchrist, 2009).

²¹ This idea evolved in the mid 19th century when a French physician, Paul Brocca, observed that those who suffered a stroke to the left frontal area of the brain, now known as the ‘Brocca’s area’, tended to lose the faculty of speech. Not long after, the Prussian neurologist, Carl Wernicke, discovered, through similar observations, that the neural basis for the comprehension of language resided further back in the left hemisphere; in the *posterior superior temporal gyrus*, a region now known as the ‘Wernicke’s Area.’ It was these two associations with language that led to the left hemisphere being referred to as the ‘dominant’ hemisphere, leading to an entrenched prejudice that while the right hemisphere may ‘add a bit of colour to life’, it is the left hemisphere that does the ‘serious’ business (McGilchrist, 2009).

argued that the deeply emotional stirrings generated by *music*, for instance, suggests that music, as a form of communication, has extremely ancient origins, long since predating the evolution of spoken language and that ultimately that the musical faculty is phylogenetically and ontogenetically older than language, for every child begins to sing earlier than to speak. In general the right hemisphere matures first. In the second year of life the left hemisphere overtakes it, with the laying down of the speech and language areas, but there is also evidence that the right hemisphere then continues developing after the left hemisphere has matured, with the more sophisticated emotional prosodic elements of language developing in the fifth and sixth years of life (McGilchrist, 2009). Modern day observations of the development of language in children confirm that the musical aspects of language precede spoken language, due to the early activation of areas of the brain which sub-serve the musical aspects of speech. Intonation, phrasing and rhythm develop first; syntax and vocabulary come only later (Brown, 2000).

Music may, McGilchrist (2009) suggests, be the ancestor of language because having evolved within the ancient subcortical structures of the right hemisphere its purpose was to promote *social cohesion* within ancient cultures. Vaneechoutte & Skoyles (1998) have argued that the development of musical skill must have been a product, not of individual selection or competition, but of group selection, a process whereby the reproduction of all genes present in a group is influenced in a similar manner by newly developed behaviours. Natural selection exploits the differences in individual rates of successful reproduction within a group, but through music the whole group would have benefited. Geschwind & Galaburda (1987) add that spoken language did not evolve to promote 'communication' (communication was already happening), but rather it evolved as a means of *mapping* the world.

Interestingly, the evidence of the fossil record suggests that we did not develop the degree of sophisticated symbol manipulation that language requires until roughly 40,000 years ago, and certainly not earlier than 80,000 years ago (McGilchrist, 2009). For most of human history, despite having a large brain and a high degree of intelligence, our ancestors managed to communicate satisfactorily without language as we understand it today, instead drawing upon the non-verbal aspects of language such as pitch, intonation, volume, rhythm and phrasing. Evidence shows that the control of voice and respiration needed for *singing* came into being long before they would ever have been required for spoken language.

There has been one very noteworthy discovery in this regard (see McGilchrist 2009: 101-103). In order to reach the tongue, the nerve which supplies it (the hypoglossal nerve) must pass through an opening in the base of the skull called the anterior condylar canal. The amount of work that a nerve has to do is reflected in its size. Thus, the size of the hole of the canal in the base of the skull indicates the amount of articulatory work the tongue of the skull's 'owner' had to do. Apes and monkeys have much smaller canals than modern humans, in relation to the nerves that serve both articulation and respiration. Yet, examination of the earliest human skeletons, from long before the time language arose, has revealed canal sizes almost indistinguishable from those of modern humans. The only reasonable explanation for this is that they were communicating through a highly sophisticated vocal system based upon the *modulation of the production of sound*, a system termed by Brown (2000) as 'musilanguage'. Some such systems still exist in the world today. For instance, some extant tribes in the Amazon basin, such as the 'Piraha', a hunter-gatherer tribe in Brazil, communicate through a language that is effectively a kind of song, possessing such a complex array of tones, stresses, and syllable lengths that its speakers can dispense with their vowels and consonants altogether and sing, hum or whistle conversations (Corbetta and Shulman, 2002). In addition, in sub-Saharan Africa, there exists a form of communication using drumbeats which has been dubbed 'rhythmic drum telegraphy'. This technique is widespread throughout the region, and through it detailed messages can be communicated over long distances (McGilchrist, 2009).

I have, during the course of my career, consistently used music as form of communication with individuals with autism; both 'verbal' and 'non-verbal' individuals, ranging from 6 to 18 years of age. I have, in the process, been fascinated and inspired by children with autism who could not apparently 'speak' but could very clearly *sing*. I have been equally fascinated- and intrigued- by older adolescents with autism who could not remember, for instance, the names of the 7 days of the week, but could nonetheless retain and perform the lyrics to countless complex songs, as well as the 'musicality'/'accented intonation' of lengthy dialogues from films, TV shows and cartoons.

Yet it should be acknowledged that not all individuals with autism are necessarily interested in, or inclined towards, music. Whilst I have yet to meet a person with autism who does not enjoy listening to music, I have likewise met many more who lack inherent confidence in their own ability to perform it. But for those individuals there are alternative 'bridges', other

equally evocative forms of communication, that may ‘accommodate’ the innately human desire to connect outwards, an ‘urge’ that McGilchrist (2009) tells us comes not from the Broca’s area (where motor speech originates) but rather from the *anterior cingulate*, a deeper lying region in the brain profoundly associated with social motivation (People with damage to this area of the brain in fact exhibit a kinetic mutism; the lack of desire to communicate despite having perfectly normal speech functioning).

Music is only *one* of many possible ‘bridges’ that this study will refer to that can help people with autism to connect with others. It is not music in terms of its ‘structural form’ that connects. Rather, it is the ‘space for connection’, the ‘narrative dialogue’, that it creates and opens up between people, and the subsequent emotional responses that it generates between people, that creates *points of connection*- a concept upon which this study is fundamentally based. Such points of connection may be similarly achieved through, for instance, drama and art, each of which have their own connective, neurological underpinnings. In relation to the former, Rizzolati *et al* (2006) have suggested that engagement in the dramatic process can trigger mirror neurons that, as previously discussed, are said to be fragmented in autism. In relation to the latter, Sacks (2008) has described cases in which there was an emergence of musical or artistic talent following strokes or other forms of damage to the left hemisphere, while Seeley *et al* (2008) have described a patient- who in the course of developing an progressive aphasia- showed a simultaneous heightening of visual creativity involving functional facilitation of posterior areas in the right hemisphere.

As chapters 4 and 5 will discuss, of most importance to recognise is the power of the *narratives*, encompassing creative forms to serve as a means of *connection* between people in a way that- for many people with autism- language cannot deliver. On its most fundamental level, in Dissanayake’s (1974: 156) words “*artistic behaviour, even though it might be private, takes the artist outside himself, puts him into a relationship with an other.*” Artistic behaviour may not be, as Sacks adds (2008: 178), “*propositional communication, [but] it is a very basic existential communication. It not only says, ‘I am alive, I am here’, but may express thoughts and feelings that cannot be expressed by speech.*”

In departing from scientific understandings of autism, to embark upon what may perhaps be regarded as, methodologically speaking, a dialectally opposed approach towards the study of autism; namely a qualitative investigation into how autism affects quality of life- this

literature review concludes nonetheless that modern neurology offers great hope to qualitative researchers practicing in the field of autism studies who are focused upon *change*, upon ‘finding bridges’ between 2 seemingly disconnected worlds because it suggests that change *is* possible- at the most fundamentally neurological of levels- in a brain that “*is not programmed and static, but is a dynamic and active superbly efficient system geared for evolution and change, ceaselessly adapting to the needs of the organism- its need, above all, to construct a coherent self and world, whatever defects or disorders of brain function befall it*” (Sacks, 1995: xv).

Furthermore, while music is only *one* of the creative art forms that may be drawn upon in moving towards a wider view of communication with individuals with autism, the creative arts are- collectively speaking- again only *one* of many mediums that a person with autism may draw upon to connect with the world around them. These mediums are uniquely individual and can only be discovered by another through *experience* of the person in question, with an entirely open mind as to what form they might take, and a critical appreciation of the fact that *connection* lies at the heart of anything approaching meaningful communication.²² “*Communication with autistic people is difficult,*” maintains Wendy Lawson (1998: 12). “*It is my belief, however*”, she adds, “*that we just operate on a different level of communication and that once this is discovered, strategies for mutual understanding can be developed.*” Lawson’s call, as an autistic person, for an exploration of different ‘levels’ of communication is echoed by another autistic writer, Jim Sinclair, who explains that “*it takes more work to communicate with someone whose native language isn't the same as yours.... you're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world*” (Sinclair, 1993: 2). The purpose of the following section is to briefly explore how these ‘levels of communication’, and disparate ‘languages’, have been approached by traditional teaching methodologies dedicated to

²² Traditionally, the degree to which people with autism are deemed to be capable of ‘communication’ is assessed most commonly by Speech & Language therapists within the Irish context using an assessment instrument known as the *CELF* (*Clinical Evaluation of Language Fundamentals*) (Semel *et al*, 2003). The purpose of the *CELF* is to identify the degree to which a person may have either an expressive or receptive language delay, or both. Assessment instruments such as the *CELF* can not address however the degree to which language can or cannot actually serve a meaningful expressive purpose for individual people, or how individuals may express themselves and connect with others through mediums beyond that of speech. Consequently, Wittmeyer *et al*, (2011: 57) have highlighted “*a need to adopt innovative approaches to facilitate the consultation of individuals on the [autism] spectrum who have no or limited speech.*”

teaching children with autism, and to demonstrate how such understandings have influenced the way in which this study has been framed.

Three established models of teaching children with autism

Introduction

In examining some of the most commonly known and well established special education approaches towards teaching children with autism, I will focus the following critique upon ABA (Applied Behavioural Analysis), TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children) and the ‘Son Rise’ programme. My rationale for focusing upon TEACCH and ABA is that within the Cork region these are the only 2 options that are presented to parents who seek a special school placement for their autistic child. ‘Son Rise’ is further explored as it was the first autism-specific programme that my case study participant- Sean- was exposed to as a child. In addition, as I will subsequently discuss, ‘Son Rise’, while being targeted at young children only, nonetheless embodies some important principles that, as I will argue, are extendable to working with older individuals with autism.

The first important point to make is that neither ABA, nor TEACCH, nor ‘Son Rise’, implies *what to teach*. The two former approaches are designed to improve the observed behaviours of the child, ABA through what is called ‘discrete trial training’, and TEACCH by focusing more upon the relationship between the child and his/her environment. Obviously, individual TEACCH and ABA schools develop their own curricula but ‘TEACCH’ itself is *not* a curricula, ‘ABA’ itself is *not* a curricula. Nonetheless, many parents who choose one or other of these options for their autistic child are, in my experience, led towards the assumption that ‘there is only one way to teach a child with autism’. This is an assumption that Schriebmann (2000), Wing (2002), and Siegel (2003) argue needs to be challenged upon the basis that there is no existing data to support such a claim. As Schriebmann, (2000: 14) puts it, “*the spectrum of difficulties, range of abilities, age of the child, culture of the family, and characteristics of the individual combine to suggest that the use of a single treatment would be poor advice.*”

Applied Behavioural Analysis

Schoen (2003) describes Applied Behavioural Analysis (ABA) as an educational practice characterized by discrete presentation of stimuli, with responses followed by immediate feedback, an intense schedule of reinforcement, data collection, and systematic trials of instruction. Sheehy (2004) adds that ABA follows from Pavlov and Skinner's accounts of the apparently lawful, predictable and controllable nature of human behaviour. Ivan Pavlov's (1849-1936) model of 'classical conditioning' found that a previously neutral stimulus, such as the sound of a bell, can elicit a response, such as salivation, because of its association with a stimulus, such as food, that automatically produces the same, or a very similar, response. Subsequently, Burrhus Frederic Skinner (1904-1990) developed a theory of 'operant conditioning', based upon the perceived relationship between behaviour and 'reward or reinforcement'. Skinner's conclusions were based upon his observations of animal behaviour, the principles of which were then applied to human behaviour. For instance, when an animal was observed performing a particular behaviour Skinner looked for its cause, and its source of control, in its history of reinforcement. Skinner's theoretical work made three basic assumptions in relation to human behaviour; that (a) it is lawful, (b) it can be predicted, and (c) it can be controlled. A 'functional analysis' of behaviour working from these assumptions would, he argued, disclose that the causes of any observed behaviour lies in antecedent events occurring in the person's environment (Rosenwasser & Axelrod, 2001).

The practice of ABA was further developed through the late 1960's and 1970's by the trained Skinnerian psychologist, Dr. Ivar Lovaas, at the University of Los Angeles. Working with hospitalized children he succeeded in reducing their self-injurious behaviours through his 'discrete trial training' (DTT) method (Lovaas, 2003). Parsons & Guldberg *et al* (2011: 57) have found "*such behaviourally-based instruction techniques applied to preschool and primary school aged children*" to be "*successful in teaching specific skills.*" "*Touch your nose, get an M&M; for some children*", Siegel (2003: 316) points out, "*this is where treatment must start*". I agree with Siegel in relation to the importance of acknowledging the significance of how "*the child [through ABA] has gone from floating through a world in which nothing was particularly connected to anything else, to knowing at least a few things he can do to get predictable, desirable rewards*" (Siegel, 2003: 317-318). However, I also draw attention to Siegel's qualification that "*over time, the goal is for the child to be able to function in a teaching environment that is less restrictive*" (ibid: 334).

TEACCH

The 'TEACCH' approach towards teaching children with autism, which originated from the work of Dr. Eric Schopler between 1966 and 1972 at the University of North Carolina, is built around behaviourist learning theories, but addresses them somewhat differently. Both methods (ABA & TEACCH) apply a high degree of invariant structure to direct a child's learning, but the TEACCH approach focuses more upon the child's interaction with his/her environment (Mesibov *et al*, 2004). In TEACCH classrooms there is generally more leeway for the child to self-initiate action with teaching materials. While there is not as much micro-management in TEACCH as there is in ABA, structure is provided by the physical organization of the environment. TEACCH is built around creating learning, working and living environments that might be called 'autism-friendly' (Siegel, 2003). Such organisation of the environment involves the assignment of each pupil an individual workstation, one designed to allow classroom staff to individualize curriculum content to that of the student's individual pace and interests. A workstation is a small confined area within the classroom in which the child has access to a set of assignments (usually three at a time) with the pupil facing a blank, non-distracting wall. Typically, the carrels are placed at 90-degree angles from one another so no one is within the personal space of anyone else. The idea is for children to learn to work independently without becoming distracted by any nearby activity (Mesibov *et al*, 2004).

TEACCH classrooms often cater for the most severely affected children with autism, those who Siegel (2003: 374) describe as "*functioning in the lower end of the moderate to severely mentally retarded range and with receptive language levels around or below the one-year level*", children for whom "*the world of spoken words is beyond their grasp.*" For such children, PECS (Picture Exchange Communication System) or VIA (Visual Interaction Augmentation) are incorporated to augment communication (Mesibov *et al*, 2004). Picture Exchange Communication System (PECS) is an educational approach that uses behavioural principles (such as prompting and reinforcement) to teach spontaneous communication skills using, objects, symbols or pictures alongside the written word (Parsons *et al*, 2011). However, one criticism that is levelled at some TEACCH programs is that the visual augmentation available through picture schedules is so advantageous for children with autism that it lowers the verbal 'press' - the need to understand a word to know what to do, or to use a spoken word to express communicative intent (Siegel, 2003).

Ultimately, TEACCH is based upon what is termed ‘structured teaching’ which refers, as Siegel (2003: 353) explains, to creating “*a very routine-based school day*” that appeals to children who “*prefer rigid, predictable routines.*” As Parsons *et al* (2011: 53) have found, there is “*evidence that structured approaches can support learning of specific skills for some children under some circumstances.*” Theoretically, in a TEACCH classroom it is always possible for the child to have some visible structure to which to refer. This visible structure may take the form of picture-based schedules, placement of curriculum materials in particular locations in the classroom, or work assignments with the same structure but varying in content from day-to-day. In addition, the TEACCH philosophy strongly values the role of parents as participants in their child’s education, which will be returned to in chapter 5. As Schopler & Mesibov (1984) point out, at the most intense level, a mother will function as an assistant teacher and work in the classroom on a regular basis.

‘Son Rise’

The ‘Son Rise’ programme (SRP), delivered at the ‘Autism Treatment Centre of America’ (ATA) in Sheffield, Massachusetts, USA, is a programme designed to help the parents of young children with autism to interact with their child more successfully by reconceptualising the child’s ‘obsessions’ as *interests* which offer a *way in* to the child’s world. Primarily, ‘Son Rise’ is about *mutual respect* between child and adult. ‘Son Rise’ operates by paying close attention to the issues of 1) judgment, 2) motivation, and 3) control. It advocates a ‘responsive style of interaction’ which means that a) the topic of play is derived from the child’s individual interests, and b) the child actively chooses when to begin and end the interaction (Beckwith and Cohen, 1992). The ATA (2011) maintains that accepting a child’s ‘obsessional themes or topics’ as entry points to developing channels of communication with him or her, does not encourage further perseveration of those interests but, in fact, helps to transform preservative, rigid play or conversation into socially appropriate, flexible, reciprocal interactions on the basis that the ‘Son Rise’ approach makes social interaction more inherently motivating for the child.²³ In an intensive ‘Son Rise’ programme *there is no*

²³ The parents of the autistic children involved in this study reported either no increase, or a decrease, in the child’s engagement in the target obsessional theme at home, after the initiation of the obsessional themed games. This finding is consistent with the findings of Charlop *et al* (1990) who used obsessional themes as reinforcers for children to complete other tasks and found no increase in the children’s use of these particular obsessional themes.

such thing as right or wrong. Judgment, throughout which are normally 1-2 week sessions, is completely suspended for the duration of the programme in the interest of A), *getting inside the world of the child* and B), *gaining the trust of the child*. Parents are challenged, as they enter a SRP playroom with their child, to suspend all of their own pre-conceptions in relation to how their child *should act* and to alternatively *follow the child*.

Approaching the teaching of ‘young people’ with autism

How children and young people with autism have traditionally received their education, as briefly explored through the 3 dominantly established autism-specific teaching methods outlined above, may be reduced to 2 fundamental points of contention; whether to attempt to ‘normalise’, to the greatest extent possible, the child or young person through a behaviourally-orientated approach, or to enter into, and ‘join’ the world of autism, in order to gain the trust of the child and, in so doing, attempt to entice the child to join us in ‘our world’. It could be contended that of the 3 approaches discussed above, only the ‘Son Rise’ approach places the importance of reciprocal communication at the heart of pedagogy.

In a speech delivered by Ruan Kaufmann (the autistic son of the programmes founder, Niell Kaufmann), in 2005, he described the founding principle of ‘Son-Rise’ thus; *“They show us the way in. We show them the way out.”* Yet this ‘inside out’ Son-Rise approach applies to children only- within the context of a playroom. There is no existing ‘method’ of teaching ‘young people or adolescents with autism’ that extends such an interpretative/exploratory approach to a more complex social world beyond the playroom, with its inevitably associated, newly emerging, adult-orientated realities and challenges, or which takes account of unfolding adult aspirations which is the focus of my case study with Sean. Rather, approaches such as ABA and TEACCH are often applied to teaching young people with autism right into their late teens.

Simultaneously, Wittmeyer *et al* (2011: 19) point out that *“studies of quality of life in adults with autism are rare”*, despite the *“obvious, though rarely considered fact”* that *“we are adults for many more years than we are children”* (ibid: 11). The study’s authors argue that educational planning for those with autism needs to be designed to cover a much longer period of a person’s lifespan than that of childhood, and be responsive to needs arising at different stages of adulthood, if we are to seriously address the issue of ‘quality of life’ as it

relates to young people with autism. Yet the literature review conducted as part of the Wittemeyer *et al* (2011) study revealed that where research literature does exist, it fails to consider what ‘quality of life’ may mean from the perspectives of young persons or adults with autism themselves, but rather exclusively prioritises outcomes related to *functional goals* alone. As one interviewee who participated in the study (who worked with disabled students in further and higher education) put it; “*Currently adults with autism may be in further education but they may have seven food hygiene certificates, rather than something meaningful*” (Wittemeyer *et al*, 2011:31). Ultimately, according to the study’s authors, “*there is little evidence in the research literature of studies specifically setting out to investigate strategies for achieving good adult outcomes when working with children. Rather, studies reflect the priority of compensating for the difficulties that arise from autism and to find ways of reducing those problems*”, concluding that, “*what is clear from [their] research is that the pattern of outcomes for many adults with autism does not match with the hopes and aspirations that young people have for themselves*” (ibid: 37-57).

Perhaps this is partly attributable to the fact that the perspectives of those with autism themselves have largely been ignored within the mainstream of traditional academic discourse in the field of autism studies. Notwithstanding the fact that academic studies of quality of life in adults and young people with autism are practically non-existent, there are rare- yet uniquely insightful and powerfully evocative- autobiographical accounts of autism that are deeply revelatory of how ‘quality of life’ in autism may be conceptualized from ‘within’ the perspectives and perceptions of a number of autistic individuals. Authors who have published personal accounts of autism include individuals such as Wendy Lawson, Donna Williams, Temple Grandin, Jim Sinclair, and Luke Jackson. Such personal accounts of autism may provide crucial insights into new considerations that may be brought to bear upon new approaches towards working with children and young people with autism (as I will further discuss in chapter 5). A key argument framing this study is that it is important to move beyond ‘systems thinking’ in educational practice (informed by what we *assume* autism to be). The first step in doing this is to explore ‘what autism is’ from the perspectives of those who actually have autism.

Exploring ‘hidden voices’ in autism studies

“*What is autism?*” Temple Grandin asks. Evocatively and reflexively drawing upon her own experience of autism she answers the question thus; “*She does not reach out and explore the world around her, but instead stays in her own inner world*” (Grandin & Scariano, 1986: 9). Temple reminds us- in one beautifully crafted sentence- that autism is fundamentally a condition of ‘aloneness’; as originally described by Hans Asperger in 1943. Thus, Temple hints us towards understanding not only ‘what autism is’ but, more importantly, *what autism feels like*. A pervasive *feeling* of ‘aloneness’ is, fundamentally, ‘what autism is’, what constitutes *living with autism*, for many people who have written of their experience of the condition. As I will describe in chapter 5, before I discovered a ‘narrative bridge’ with which I could connect with Sean (in the classroom-based context), he went through periods of *weeks* in which he barely uttered a single word to anybody around him, preferring to remain alone, ‘imagining’ or ‘pretending’ in relation to his imaginary characters in his own ‘virtual world’. A ‘world under glass’ is a commonly invoked metaphor used to describe living with autism by those who have written with first-hand experience of the condition. “*My world under glass*”, Donna Williams recalls was “*a place with reinforced invisible glass windows, a self-made womb to replace the womb I had now outgrown and through which I had been able to view ‘the world’ as I sat back and enjoyed the show*” (Williams, 1994: 9).

The striking metaphor of living within a solitary ‘existence’, perpetually- and potentially eternally- trapped behind a ‘pane of glass’ describes a person *who can see, but cannot reach*. Glass is transparent yet impenetrable. The metaphor suggests that people with autism who may seem disinterested in the ‘other world’- the world beyond the glass divide- may be far from disinterested in the world beyond them, but rather they may be simply unable to reach it, without the help of others. The disability is not one of disaffection or dissatisfaction, but rather one of ‘*unreachability*’. “*One of the best ways of understanding what autism is like*”, Wendy Lawson explains, “*is to imagine yourself as a perpetual onlooker. Much of the time life is like a video, a moving film I can observe but cannot reach. The world passes in front of me shielded by glass*” (Lawson, 1998: 5).

It is reasonable to suggest that this innate feeling of aloneness, and the consequent struggle to ‘cross the bridge’ to the other world, is not helped by a very real, ingrained sense of fear, all-too-often constructed by the external environment. Such fears may be somewhat attributable-

but not limited- to internal, bio-genic factors such as struggling to cope with the continual bombardment of sensory stimuli as previously discussed. Yet, *the actions of others*, this study contends, plays *the* crucial role in dictating whether an autistic person may spend an entire lifetime existing within a protective shell (a world of often ingenious, yet self-enclosed, adaptation), or whether he/she may be enticed across the ‘neurological divide’ - from the *safety* of the left hemisphere to the *possibility* of its right-hand-side counterpart when established *mutual acceptance* and *trust* form the foundations of such a ‘bridge’. In Sean’s case, as it transpired (and will be discussed in chapter 4), his very low sense of self-esteem may have been a crucial contributory factor in his almost total withdrawal from social life. All 5 authors discussed in this section reported instances of pathological bullying in school. Yet all ‘made it through’ to tell their story. But how? The answer is that *they all adapted in different ways*: they all searched for, and ultimately found, a place to ‘be’, a place to ‘exist’, a ‘place’ in which they were *safe* until the ‘other world’, the ‘social world’ made it possible for them to join ‘it’.

Luke Jackson found that ‘place’ in Tae Kwon Do, while Wendy Lawson found it in the “*lifesaver*” that was film. “*I copied characters from the American adventure programmes, even taking on their accents,*” Wendy recalls, “*...by becoming an adventure hero I hoped to gain an acceptable identity*” (Lawson, 1998: 18). Temple Grandin found her ‘place’ in designing cattle chutes in the pursuit of more humane approaches towards animal slaughter, while Jim Sinclair found the place where he most comfortably ‘existed’ lay within the process of writing. However, one of the most fascinating accounts of adaptation (to an entirely intolerable world) may be found in the writings of Donna Williams, 2 of whose novels, ‘Nobody Nowhere’ (1992), and ‘Somebody Somewhere’ (1994), describe- in extraordinary detail- the construction of an entirely imaginary, artificial world (that bore striking resemblances to Sean’s world of pretence) based upon the aforementioned characters of ‘Carol’ and ‘Willie’ that, in spite of their subjective artificiality, were no less than projections of Donna herself, characters positioned within ‘safe distances’ between the autistic and neurotypical worlds, that allowed Donna to tentatively explore the outside world, but escape and hide from it when necessity demanded.

‘Carol’ was invented shortly after Donna slipped, and eventually disappeared, behind her ‘world of glass’ in response to her growing personal dissatisfaction with everything she perceived herself to be. “*Carol was everything that people liked*”, Donna tells us, “*Carol*

laughed a lot, Carol made friends. In the mean time, Donna had disappeared. I had discovered choice. I wanted to live in Carol's world. In the darkness of a cupboard I found Carol within myself. I was, by this time, five years old" (Williams, 1992: 21-22). Donna's 'transition' from the world of autism to the neurotypical world was (due to a horrific set of personal circumstances) far from a peaceful one. *"I would cry and look desperately into Carol's eyes reflected in the mirror"*, Donna reflects, *"wanting to know the answers to the way out of my mental prison. I began to hit myself in frustration- slapping my face, biting myself and pulling out my hair"* (ibid: 22). The greatest tragedy of Donna Williams' story is, in my view, that she was *forced* to sacrifice one world for the other. *"The windows of 'my world' had been broken"*, she muses, *"and I was left rawly exposed to the enemy"* (Williams, 1994: 9). She was forced, in her own words, to *"throw 'my world' into the jaws of 'the world'"* (ibid: 8) without ever being afforded any choice in the process.

Essentially, the tragedy of Donna Williams' story lies in her 'discovery' of autism as an inherently negative condition. *"After twenty-five years"*, she tells us, *"of wondering what sort of stupid, mad, or disturbed person I was, I had stumbled across a word that helped explain 'my world'. That word was 'autism'. Rejecting 'my world'"*, she concludes, *"was like amputating my own limbs one by one, but it would have to be done"* (Williams, 1992: 8). Yet perhaps the ultimate tragedy of Donna Williams' account of her experiences was that she was never facilitated in appreciating how wonderfully unique her own world actually was; one to be cherished, remembered, and occasionally revisited- forever.

Authors such as Temple Grandin and Wendy Lawson, who have had less tragic circumstances to contend with, have had 'better adult outcomes' than Donna primarily because they were never forced to reject their own private, unique worlds, but were rather enticed towards 'slipping in and out of them' in accordance with their own preferences and personal needs at different times. A key conclusion of this study, which is traced throughout chapters 4 and 5, is that a person with autism should never be forced to reject their own private world. *"How peaceful it is"*, Wendy Lawson reflects, *"to withdraw from the complicated world of human relationships! I do however enjoy the presence of a friend and feel so content in the presence of one who is willing to take me as I am.... now I have the ability to choose whether I live in my own world or whether I join the 'world' of those around me"* (Lawson, 1998: 15-136). *"All of us"*, Temple Grandin adds, *"need a private place...autistic people need their secret places in which they can hide and retreat into their*

own inner world. After all, autism is a 'withinness' disability, and autistic people need the security of their own hideaways" (Grandin & Scariano, 1986: 151).

Those who have lived with autism, this study contends, know 'what autism is' better than any practising professional or researcher in the field of autism studies. *They are the experts* for no other reason than that *they know- first hand- what it is like to have autism*. The task for researchers, this study further contends, is to draw out precisely that, even if the person is unable to tell their own story without help from another. By telling 'Sean's story', and in the process presenting the beauty, purity and complexity of his multiple worlds to the reader, I present Sean as nothing less than an expert on his own condition. "*Luke Jackson*", Tony Attwood writes in the forward to Luke's acclaimed book, 'Freak's Geeks and Asperger Syndrome' (2002), "*is an expert on the challenges encountered by his peers*" (Jackson, 2002: 9). "*I hope that in writing a book myself*", Luke wrote (at the age of 13), "*I will have answered some questions that other adolescents are asking and at the same time helped parents and carers to help their child more. Another big reason for writing this was the hope that professionals of any sort may read it and begin to understand the many, many people who are similar to me*" (Jackson, 2002: 13-14). Such a book, written by a young teenager for other young teenagers, surely holds out more hope than traditional theories of autism for autistic youngsters of the kind who, interviewed during the course of the Wittemeyer *et al* study, were found to be "*deeply aware of 'being different' or 'having lots of things wrong with them*" (Wittemeyer *et al*, 2011: 28).

This sense of hope- of possibility- characterises all 5 texts of authors who have autism discussed in this section. "*I offer hope to parents and professionals who deal with autistics because I was labelled autistic*" Temple Grandin tells us (Grandin & Scariano, 1986: 11). "*Autism is a way of being*", Jim Sinclair reminds us, "*it is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence*" (Sinclair, 2009: 1). "*Dr. Asperger may have defined the syndrome I was born with*" Wendy Lawson informs us, "*but I have decided his descriptions of my limitations will be the means to remove the bars from my cage- not reinforce them*" (Lawson, 1988: 4).

Finally, Donna Williams leaves us with a 'bitter-sweet' reflection upon how she coped with leaving Willie and Carol behind, with an intensity to move us as much as to 'inform' us. "*In writing the autobiography*" Donna explains, "*Willie, Carol, and I, each began to become*

fully aware of who each of us was and what each of us had lived. A self must have a past. The book was the only place in which that past was strung together as a whole, but it was a start. We had foundations to build upon.... I didn't need Willie and Carol anymore. I needed Donna. I said goodbye to the characters who had sustained me for so long and welcomed the me I wanted to know better" (Williams, 1994: 13-17). One positive outcome of the case study presented in chapter 4 was that Sean- in finding a sense of identity and purpose in his life- never felt compelled to say goodbye to his imaginary characters that were so much part of that life, but rather that he found ways to bring aspects of those characters' personas- in particular their utopian ideals- into the real 'unjust', social world, in order to make a difference in the lives of people who he felt were less fortunate than himself.

CHAPTER 3- METHODOLOGY

Introduction

In chapter 1, I explained how the rationale for the case study presented in this thesis took hold in April 2010 when the parents of one of my pupils, Sean Cronin, asked me for advice as to how a long-term programme may be placed in motion that may enrich his ‘quality of life’. Yet, this presented something of a dilemma. Prior to this request I knew Sean only as one person or entity- my pupil- a pupil with a significant number of difficulties associated with the autistic condition which table 3 below sets out.

Table 3- A cross section of Sean’s difficulties

<i>Paradigm</i>	<i>Sean’s diagnosis/presentation (difficulties)</i>	<i>Associated theories/diagnostics</i>
<i>Psychiatric</i>	Autism in the severe range.....	F84.0- ‘ Childhood Autism’, ICD-10 (1993)
<i>Clinical</i>	Sensitivity to sound..... Low strength and endurance..... Gastrointestinal difficulties..... Repeating words and phrases..... Unusual movements of the hands..	Sensory integration disorder Muscular hypotonia Celiac Disease Echolalia Stims/tics
<i>Cognitive-psychological</i>	Comprehending the points of view of others.....	Theory of Mind/Mentalising deficit
<i>Neuro-psychological</i>	Shifting attentional set..... Achieving global attention.....	Executive functioning deficit Weak central Coherence
<i>Neurological</i>	Self-regulation of time..... Memory difficulties.....	Temporal perception deficit Retroactive inference difficulties

The difficulties listed in table 3 above are commonly conceptualised as ‘within-child’ deficits associated with autism. Yet, as chapter 1 alluded to, approaching the issue of ‘quality of life’, as it relates to Sean, demanded a suspension of judgment on my part in relation to Sean’s apparent limitations, in favour of a multi-contextual approach based upon the sharing of meaningful experiences with him across a multiplicity of contexts. Only then could the study approach the objective as set out in chapter 1; that of bilaterally exploring both Sean’s ‘human condition’ as well as his ‘autistic condition’ in order to ask- ontologically speaking- where the dividing lines may be said to exist between the two. Thus the research design was based upon 31 days of fieldwork, carried out with Sean between June 8th and July 30th 2010, each day consisting of a specific activity as listed in table 4 below. The decision to conduct the study over 31 days was a decision jointly arrived at between Sean’s parents and I, who

agreed that approximately 30 days, over a 2 month period of time, would be appropriate for Sean- the programme would ensure that he had a substantially lengthy summer activities programme, but one which also provided adequate time to spend with his family at home. As I will discuss subsequently the activities below were not fixed in advance but developed over the period of fieldwork, and were continually responsive to the wishes of Sean and his family.

Table 4- Fieldwork activities

Day	Date	Primary activity/activities
1	08/06	Boating cruise around Kinsale harbour & the Bandon River, West Cork
2	09/06	Visit to Wilton library & climbing on artificial climbing wall, Cork City
3	10/06	Viewing of DVD 'Click', Sean's family home, Douglas, Cork
4	11/06	Shopping trip 1 in Cork City & visit to 'Douglas Court' shopping centre
5	14/06	Driving yacht around Crosshaven harbour
6	15/06	Swimming in 'Leisureworld' leisure complex, Bishopstown, Cork
7	16/06	Trip to Murtleville Beach, West Cork
8	17/06	Horse riding lesson at Hop Island equestrian centre, Carrigaline, Cork
9	18/06	Visit to the Granary Theatre, Cork City- '2 Dimensional Life of Her'
10	21/06	Trip to Inchadonny Beech, West Cork
11	22/06	Visit to 'Titanic Museum', Cobh Heritage Centre, West Cork
12	23/06	Viewing of 'Father Ted' DVDs, Sean's family home, Douglas, Cork
13	01/07	Trip to cinema, Mahon Point Shopping Centre, - 'When in Rome'
14	02/07	Swimming in 'Trabolgon' holiday village, Middleton, East Cork
15	05/07	Bowling in 'Planet Entertainment Centre', Cork City
16	06/07	Karting in 'Kartworld' motorsport centre, Watergrasshill, East Cork
17	07/07	'Westlife' concert at the Marquee Arena, Cork City
18	08/07	Trip to cinema, Mahon Point Shopping Centre, - 'Shrek the Third'
19	09/07	Golfing lesson at Muskerry Golf, Co. Cork & visit to Mrs. Peg King
20	12/07	Shopping trip 2 in Cork City- preparation for Carrauntoohil climb
21	13/07	Rest day 1- O'Brien's Cafe, Wilton Shopping Centre
22	14/07	Swimming in 'Trabolgon' holiday village, Middleton, East Cork
23	20/07	Swimming in 'Leisureworld' leisure complex, Bishopstown, Cork
24	21/07	Rest day 2- 'Costa Cafe', 'Douglas Court' shopping centre
25	22/07	Training hike- 'Barry's Way', Gungan Barra, West Cork mountain range
26	23/07	Tae Kwon Do lesson at 'Leisureworld' leisure complex, Bishopstown, Cork
27	26/07	Swimming lesson at 'Leisureworld' leisure complex, Bishopstown, Cork
28	27/07	Trip to cinema, Mahon Point Shopping Centre, - 'Inception'
29	28/07	Ascent of Carrauntoohil, McGillcuddy Reeks, Killarney, Co. Kerry
30	29/07	'Mamma Mia' concert at the Marquee Arena, Cork City
31	30/07	Shopping in 'Douglas Court' shopping centre

A participatory approach

In the following section I will discuss the 3 levels of participation that underpinned this study. The first relates to how the concept of participation was conceptualised and applied to a wide group of fieldwork participants. The second relates to my own positionality as an active research participant (a ‘player’ in the action as well as an observer/reporter), while the third discusses how Sean was facilitated in becoming an *active* participant in the research process; how his views and preferences were respected and responded to a *guiding principle* of the research act.

Participants as ‘co-researchers’

Whilst 12 days (38.7%) of the fieldwork activities consisted of shared activities between Sean and I, a further 19 days (61.3%) involved 17 project participants who engaged with Sean in a number of varied activities in the Cork (city and county) & Kerry regions. These participants included Sean’s immediate family (both parents & 2 younger brothers), 2 support workers, 1 of Sean’s classmates, his Special Needs Assistant & her 2 young children, as well as 7 professional activity leaders as table 5 below outlines (The decision to include some real names is discussed at the end of this chapter).

Table 5-Fieldwork activity participants

<i>Day</i>	<i>Date</i>	<i>Additional activity participants (AL=Professional activity leader)</i>
1	08/06	None
2	09/06	Local service provider support worker
3	10/06	Conor (12) & Ciaran Cronin (8) (Sean’s brothers)
4	11/06	None
5	14/06	Mr. Brendan Cronin (AL) & Mrs. Francis Cronin (Brendan’s wife)
6	15/06	Ms. Joanne Lenihen (Disability Officer)
7	16/06	Local service provider support worker
8	17/06	Mr. Jason Carey (AL)
9	18/06	None
10	21/06	None
11	22/06	None
12	23/06	None
13	01/07	None
14	02/07	John Meehan (Sean’s classmate)
15	05/07	Loretta O’Sullivan (SNA) & her 2 children- Abby (8) and Ross (5)
16	06/07	Mr. Gavin Daly (AL)
17	07/07	Mrs. Noreen Cronin

18	08/07	Ciaran Cronin & Ciaran's home support worker
19	09/07	Mr. Hugh O'Leary (AL) & Mr. Joe O'Leary
20	12/07	None
21	13/07	None
22	14/07	Conor Cronin, Ciaran Cronin & their home support worker
23	20/07	None
24	21/07	None
25	22/07	Mr. Joe O'Leary (AL)
26	23/07	Mr. Corin Morgan Armstrong (AL)
27	26/07	Ms. Joanne Lenihen (AL)
28	27/07	Ciaran Cronin
29	28/07	Mr. Joe O'Leary (AL) & Mr. Pat Falvey (AL)
30	29/07	John, Noreen, Conor & Ciaran Cronin
31	30/07	None

The 17 participants who partook in the study were ultimately 17 indispensably valuable points of what Cohen *et al* (2011: 73-78) call 'focalisation', "*well-defined lenses*" through whose eyes "*narrative episodes unfold*" allowing researchers to "*address questions of voice in their participants.*" "*Good case facilitation*", Miller & Kantrov (1998: 4-5) tell us, "*creates an environment in which different perspectives can be articulated and considered*", allowing for as Wimpenny (2010:93) puts it, "*ownership of the agenda amongst participants.*" As chapter 4 and its associated interviews reveal, I gained invaluable insights into Sean's *strengths* through the views of participants who shared real, meaningful experiences with him throughout the course of the project. Suspending my own assumptions in relation to the apparently limiting effects of Sean's difficulties and 'taking a leap of faith' *with Sean*, was immeasurably influenced by the faith placed in him by others, including many of those listed in table 5.

Respecting the involvement of participants as 'co-researchers', Wimpenny (2010: 92) tells us, may greatly contribute to the authenticity of participatory research by "*allowing for the production and generation of knowledge as a shared task.*" Many of the project participants who took part in activities with Sean, and who spoke on his behalf on occasions such as his 'awards night' (14/12/2010) (which will be described subsequently), were close personal friends of mine, members of my own family and friends of my family; people whom I could trust 100% to act and speak in Sean's best interests. Those people included my father Joe O'Leary (mountaineering), Joe's friends Pat Falvey (mountaineering) and Brendan Murphy (speaker on 14/12/2010), my uncle Brendan Cronin (yachting), as well as 2 of my cousins' husbands, Hugh O'Leary (golf) and Corin-Morgan Armstrong (Tae Kwon Do). Approaching

participation by inviting trusted friends and family members to participate in the study held untold advantages for 3 key reasons. Firstly, in relation to the ‘riskier’ activities, I could place absolute faith in their expertise as professionals in their fields, as well as having the assurance- based on my experience of them as individuals- that they would not push Sean beyond his limits of comfort in order to ‘succeed’ in activities. These were participants who I knew would be sensitive to the approach of ethically-informed fieldwork with vulnerable young people being, in the words of Merriam (1988: xi), “*more about process rather than outcomes, discovery rather than confirmation.*”

Secondly, by involving highly regarded friends and family members in the study I was able to bring an honesty and warmth to the ‘interview’ process that consequently produced data of immense richness. These were data that I inherently *trusted* and thus the insights and perspectives that emerged in the course of the interviews in relation to Sean’s strengths were put to immediate effect *within* the period of the fieldwork itself, rather than leaving them for consideration to the latter stages of data analysis. Good case studies, in the words of Cohen *et al* (2011: 292) “*should be a ‘step to action’....beginning in a world of action and contributing to it....their insights [being] directly interpreted and put to good use.*” I very deliberately invited participants into the study whose opinions, intellect and warmth of personality (in addition to their expertise in their respective fields) I hold in the very highest of esteem. These were people, 2 of whom Sean had previously met (Joe & Pat), whom I was certain, without exception, would not only challenge Sean positively but would bring a genuine sense of interest, enthusiasm and warmth to the participation process.

Thirdly, because I was fortunate enough to have participants who genuinely *wanted* to participate in activities with Sean, I was able to ensure that the bonds created between them and Sean during the course of the fieldwork could be potentially sustained beyond the course of the research project. As Wimpenny (2010: 91-97) reminds us “*if a participatory research project does not make a difference in a specific way for the participants, it has failed to achieve its objectives....The writing-up and dissemination of the findings of participatory action research should not detract from the ongoing impact of the inquiry on the individuals’ lives.*”

Sean's parents as 'co-designers'

In addition to the role that trusted friends and members of my own family played as 'co-researchers' in the study, it is important to further acknowledge the role that Sean's parents played as active participants in the research process. Crozier (2000: 125) reminds us that "*at a very basic level*", in the educational process, "*parental involvement that is based upon understandings of participatory democracy can only be brought about if mutual trust and respect is established.*" The importance of involving parents in special education programmes will be further discussed in chapter 5, but for the meantime permit me to acknowledge the following. To say that Sean's parents, John and Noreen, were 'co-researchers' in the project would in fact be an understatement of the role they played within it and their contributions to its outcomes. They were actually, like Sean, 'co-designers' and 'co-authors' of the project. It should be noted, for instance, that the idea to bring Sean boating in Kinsale on day 2 was, in fact, John's idea on the morning in question (I had a different activity planned for Sean but John made the obvious point that on such a glorious day, what better way to spend it than sailing, in an open top boat, around Kinsale harbour). Similarly, our excursion to the 'Westlife' concert (Sean, Noreen & I) was as much Noreen's idea as it was mine; borne out of one of our many day-to-day conversations wherein I remarked that Sean had taken a 'domino effect' attraction to a number of 'Westlife' songs during our car journeys together. Meanwhile, the genesis of activities involving Sean's 2 younger brothers- such as trips to the cinema and 'Trobolgan' leisure centre- were entirely attributable to Sean's parents' suggestion of involving Conor and Ciaran more in the programme of activities with their older brother. Finally, the 'Mamma Mia' concert on the 2nd last day of fieldwork was not a 'planned' for activity by me, but was actually a 'thank you' gift to me to me upon completion of the fieldwork, an invitation to spend an evening of celebration of Sean's achievements with a family that had welcomed me so wholeheartedly into their home and their lives.

Being a research participant and observer

"*There are two principal types of observation-* Cohen *et al* (2011: 297) tell us- "*participant observation and non-participant observation.*" The former is traditionally associated with 'participatory action research' whilst the latter is more closely associated with 'ethnography'. What distinguishes these two approaches in qualitative research is the degree to which (if

any) the researcher becomes personally involved in the research process, as well as the extent to which he/she is intent upon affecting change for the group or person in question.

Ethnography is primarily, Woods (1986: 4) explains, “*a description of the way of life of a race or group of people...their beliefs, values, perspectives motivations....it tries to show how these things develop or change over time or from situation to situation...from within the perspectives of the group’s members.*” Action research, on the other hand is more focused upon change, a process in which Cohen *et al* (2011: 297) explain, “*observers engage in the very activities they set out to observe.*” ‘Participatory action research’ is, Wimpenny (2010: 89-90) adds, “*a method of research about a group of people who are affected by some problem or issue and decide to get together to work out how they want to tackle the problem.*”

It would be misleading to suggest that the case study presented in this thesis was either strictly ethnographic or action-research orientated in nature.²⁴ Clearly, the study could not be strictly ‘ethnographic’ in the sense of me adopting an exclusively ‘non-participant’, ‘observational’ role as researcher. As chapter 4 describes, and chapter 5 further discusses, the 2-month period of fieldwork was as much characterised by the development of a growing relationship, an evolving friendship- between Sean and I- as much as it was characterised by the bonds that he developed with other key fieldwork participants. This study can not over-emphasise enough the importance of consistency, mutuality and ‘being with’ the research participant on a day-to-day basis, when the subject of research is a vulnerable young person. Yet there were times when it was possible- and indeed in Sean’s best interests- for me to ‘retreat from the action’ and assume a more observational role. These were times when having ‘set the stage’ for particular activities I was able to ‘shift lenses’ and allow the ‘drama’- the lived narrative- to unfold before me without interference and, in the process, focus upon recording (using camera and video camera) the human dynamics at play across various ‘sites of experience’. Ultimately, the instances in which I assumed a more or less active role in activities were largely dictated by circumstance. Thus, I did not assume the role of ‘participant’ on one day and ‘observer’ on the next, but rather alternated and shifted between these 2 roles as circumstances demanded and as opportunities for observational learning presented themselves, on a day-to-day basis. In addition, there were times-

²⁴ In any case, as Holm (2008) notes, the concepts of action research and ethnography are of late becoming closer and closer drawn together because recent ethnographic work has taken on aspects of action research by being more participatory, as well as being focused on change.

particularly during the course of activities involving Sean's family (as chapter 4 will describe)- when it was important, and only respectful, to depart from my role as 'researcher' in favour of one as 'guest' who was invited to share in family experiences.

Sean as active participant

Traditionally speaking, for a research project to qualify as being truly participatory in nature, its participant(s) would, as Porter & Lacey (2005) explain, be required to have been involved in the collaborative development of any or all parts of the research process, including setting the agenda, carrying out the research, analysing the data, as well as dissemination of its findings. If participatory research is not conducted in this way, Swain (1995: 74) asserts, research will only serve to "*confirm rather than challenge existing social constructions of special educational needs.*"

Ware (2003) argues that while we may not be able to collect the views of people with profound and multiple learning difficulties with any degree of certainty, this should not exclude them from the process. As Peters (1995) puts it, participatory research is a 'search' *with* people rather than *on* people, and should be based upon the development of democratic and reciprocal relationships between the researcher and the researched. Developing democratic relationships, Freedman (2001) maintains, is not a purely 'linguistic activity' but more importantly lies in the researcher's sensitivity to the individual's mood- learning how to 'read' an individual's expressed like or dislike for certain activities on a day-to-day basis. Of primary importance, Bogdan & Biklen (1982) add, is learning to understand human behaviour from the subject's own frame of reference. This can only come about through what Peters (1995) terms 'acceptance in communication', and Clegg (2003) terms an 'ethical relationship' which involves accepting that the other person has a point of view which, whether you agree with it or not, is valid to that person and worth listening to.

Encouraging Sean to make more choices in relation to the activities we partook in on a day-to-day basis, as the fieldwork progressed, was a crucial aspect of the research process. (Thus, for instance on certain mornings when I had a particular activity planned for the day and Sean expressed an interest in doing something else, I respected this- and in so doing- allowed for a democratic relationship to develop). Developing democratic relationships in participatory research, this study will attempt to demonstrate, ultimately amounts to, as Peters (1995: 75)

puts it, “*becoming truly empathetic, the instinctual process which amounts to not only a shared understanding, but a shared sensitivity between two people.*”

The ‘interpretative’ paradigm

Rather than asking whether the case study presented in this thesis is strictly ‘ethnographic’ or ‘action research’ orientated in nature, perhaps it is more apt to consider what ‘paradigm’ it may be most closely associated within the broader field of qualitative research. In the following section I suggest that the case study presented in chapter 4 may be located-theoretically- within the ‘interpretative paradigm’.

Qualitative research advocates a fundamentally *naturalistic* approach towards inquiry, an approach that is ‘focused yet flexible’, one that with the benefit of having an open-ended research design, allows the researcher to explore a number of ongoing, ever-changing hypotheses that evolve throughout the course of lived human experience (Peters, 1995). A ‘paradigm’, meanwhile, is a way of looking at or researching phenomena- ‘a world view’, an ‘interpretative framework’, a ‘basic set of beliefs’ or principles that underpin the identity of a research community and guide action (Guba, 1990).

Researchers working within the interpretative paradigm are concerned with understanding the subjective world of human experience. They begin with *individuals* and set out to understand their interpretations of the world around them (Cohen *et al*, 2011). The approach is ‘idiographic’, in that the focus is upon the importance of the subjective experience of individuals in the creation of the social world; in “*a subjective, relativistic social world rather than an absolutist, external reality*” (Cohen *et al*, 2011: 6). Thus from an interpretative perspective the hope of a universal theory which characterizes the normative outlook gives way to multifaceted images of human behaviour as varied as the situations and contexts supporting them. Consequently, interpretative researchers often adopt the case study approach to social phenomena because case study is a design particularly suited to situations where it is impossible to separate the phenomenon’s variables from their context (Yin, 1984).

The case study presented in chapter 4 fits well within the ‘interpretative paradigm’. It is presented as an exploratory journey that attempts to explore ‘who Sean is’ through multiple lenses, through ongoing interpretations and re-interpretations of data that emerged from

multiple lenses, in an *inductive* manner in which new multifaceted insights gave rise to new questions and angles of inquiry.

Key shifts in the study

At this point it is perhaps worth re-stating the 3 broad research questions that underpinned the study at its outset. These questions were:

1. What is 'autism' as it relates to Sean's 'autistic' condition and his 'human condition' and what are the implications of this for his 'quality of life'?
2. What methodologies and methods of data collection are most 'useful' and ethically appropriate in exploring this question?
3. How can these questions be explored across various contexts or 'sites of experience'?

In approaching the first question above, I began with a concern to investigate Sean's 'world of autism'. In April 2010, I had created a short 2 minute DVD of Sean 'pretending' in a number of contexts- an extraordinary process in which his index movements help him to replay extremely complex, entirely constructed, private narratives in his mind.²⁵ Ever since I had first met Sean (in June 2008) I had been fascinated by his 'world of pretence'. In fact, it struck me as being somewhat 'odd' that he would spend so much time engaged in pretence when the very concept of pretence (the 'crucible' for 'theory of mind') is something that is assumed to be chronically delayed or non-existent in children with autism. My review of the academic literature found no material relating to *extreme pretence* in autism. However, Donna Williams' fascinating account of an entirely constructed world of her own- complete with the imaginary characters of 'Carol' and 'Willie', as described in chapter 1, bore a striking resemblance to Sean's extraordinarily complex internal world which was at one point centred around his imaginary hero-protagonist, 'Aron'. The 'Aron Narratives' (appendix G) consist of 25 drawings and 4 written dialogues produced by Sean which, when pieced together, illustrate an extraordinary narrative journey that he undertook in his private world for over 6 months.²⁶

²⁵ Having gained the consent of Sean's parents I played these clips for a cross-section of random individuals, all of whom viewed Sean's pretending as being most unusual; behaviour that they had never before come across.

²⁶ In terms of approaching the analysis of the artwork of pupils with autism, I suggest that to adopt an 'art as therapy' approach in schools may be of less value than the un-subjective sharing of artistic processes in an entirely non-judgemental fashion, when the focus is finding a 'way in' to the internal world of the person with autism. While 'art as therapy', traditionally speaking, imposes a specific set of understandings in its practice, the

Prior to this study I had hundreds of fragmented, disconnected drawings of ‘Aron’, ‘Ciara’ and other imaginary characters that inhabited Sean’s private world. Whilst I suspected strongly that there *had* to be some deep *connection* between Sean and the imaginary invented characters that inhabited his constructed world, I had yet to find a means of exploring the *purpose* of that connection. Were they characters to hide behind to protect him from an external world that he didn’t want to spend too much time in? Or were they ‘instruments’ with which to explore the confusing motivations and actions of those who inhabit the external world, with all of its associated inconsistencies and contradictions? Or were they *actual projections of self*, embodying and reflecting characteristics of personality, identity, morality and motivation? As I will discuss in chapter 5, Sean’s characters served, in fact, all 3 purposes- at different times and within different contexts in the study. However, the purpose of this section is to briefly outline how and why key shifts occurred in approaching Sean’s ‘autistic condition’ and his ‘human condition’ over the course of the study. In approaching the former, Sean’s ‘autistic condition’, I was intent- during the initial phases of the study- upon learning more about how Sean mentally absorbs, processes, deconstructs and reconstructs narratives (such as DVDs, comics and video games), as well as how subsequently *communicates* reconstructions of those narratives verbally (usually in the form of questions) and physically (using his fingers and thumbs). Thus day 3 of the fieldwork was spent in Sean’s home, watching DVDs with him- noting the movements of his fingers, and the dialogues he whispered under his breath. However, I quickly abandoned this home-based approach towards investigating Sean’s inner world of pretence in favour of a more socially interactive approach for 2 reasons.

Firstly- as mentioned in chapter 1- as the fieldwork progressed realised that I was learning far more about Sean’s internal world of pretence throughout the normal day-to-day course of social activities than I had originally anticipated. Increasingly, as the fieldwork progressed, he would ask the most random and fascinating of questions (which were often really statements phrased as questions), such as if he could “*make the garden of Eden into a planet.*” Secondly, I realised that social encounters wherein Sean formed close bonds with

method of analysing Sean’s artwork in this study was based more upon a guiding ethic of non-judgementalism where the aim is not to attempt to ‘fix’ but, rather to better understand the person in question. The fundamental drawback of ‘art as therapy’ lies, in my view, in the interventionist nature of the client-therapist relationship. According to Dubowski (2004: 49), “*the art therapist, as a clinician, is first and foremost concerned with treating the patient.*” Stott & Males (2004) further note that the roots of art therapy are firmly based in psychotherapy, and that the psychiatric model predominates in art therapy training courses.

others, people whom he was compelled to communicate something of himself to (particularly my father Joe) would reveal not only how Sean's private world operates in the mechanical sense, but how *meaningful* characters and protagonists from that ever-shifting world (both characters imported from external narratives and those entirely constructed from scratch) actually were to him. This was illustrated on the occasion, for instance, (described fully in chapter 5) when during an emotional and spontaneous divulgence of the death of his Aunt Liz to Joe, Sean asked Joe if St. Kevin (referenced in an episode of 'Father Ted') would look after Liz in heaven.

In light of these new emergent understandings, my approach towards investigating how Sean operates in a world of pretence widened considerably. After day 3, the days in which I did follow the narrative 'line of inquiry' I did so in social contexts such as trips to the cinema (with his brothers), the theatre (with myself), and the 'Westlife' concert (with his mother). In so doing I realised the potential of *shared* narrative to create often deeply beautiful points of connection between Sean and others. It was only by discovering how narrative can serve as such a powerful means of connection with others in Sean's external world, that I began to appreciate and understand more about the meaning and relevance of his fictional characters in his internal world.

In approaching the other aspect of Sean's 'self'- his 'human condition'- at the outset of the project, and in approaching the extraordinarily broad phenomenon of 'quality of life' as it relates to Sean, I began by asking the most basic 'functional' of questions. Which activities, for instance, would Sean like the most: golf, boating, yachting, self-defence, go-karting, horse riding, hill walking, bowling, swimming, visiting the beach or visiting the city? Perhaps then I could extract some common features from the activities that he enjoyed the most and make suggestions as to how to address his future recreational needs. Thus I began preparing the logistics and additional participants for these activities over 32 days. However, the focus of inquiry in approaching Sean's 'external world' again widened when I realised very quickly that the *person associated with the activity* was as much a source of wonder and interest for Sean as the excitement generated by the activity itself. A new avenue of inquiry thus presented itself; namely how people who share experiences with Sean are firstly *internalised* by Sean as friends (in terms of their interaction with him) and ultimately how they may be *maintained* as friends in a widening, yet ultimately *connected* social circle (a phenomenon explored as 'Sean's web of personal linkages' in chapter 4). Simultaneously, the unexpected

finding (on day 5- yachting) that Sean's ability to maintain extremely high levels of both focused yet flexible attention when placed in *control* of his own actions led to a further exploration of his performance in control-based activities. Meanwhile, the again unexpected finding that Sean had an almost pathological fear of making *choices* led to activities which investigated (by further exploring the concept of *purpose*) how he could be encouraged to make more choices for himself. Finally, perhaps the most significant shift of all occurred after the discovery of the depths of Sean's desire to help others less fortunate than himself, bringing the fieldwork activities towards an unforeseen exploration of the concepts of *challenge* and *risk*.

A multi-method case study approach

Case studies involve looking at a case or phenomenon in its real-life context, usually employing many types of data (Robson, 2002). Employing what is termed a 'multi-method approach' (Denzin & Lincoln, 2008) or a 'mixed method design' (Yin, 2009) in the collection of data throughout the course of this study was important for a number of practical and ethical reasons. Foremost amongst these is that *because* qualitative research is committed to the naturalistic perspectives of qualitative researchers, and to their interpretative unveiling of new understandings in relation to the unpredictability of the human experience, it rather naturally lends itself to the view of Denzin & Lincoln (2008: 29) that "*no single method can grasp all the subtle variations in ongoing variations in ongoing human experience*", as well as that of Cohen *et al* (2011: 23) who espouse that 'mixed method research' holds out the advantage of "*meeting the need of the research questions rather than the methodological preferences of the researcher.....enabling meanings in data to be probed, corroboration and triangulation to be practiced, richer data to be gathered, and new modes of thinking to emerge.*"

In chapter 1, I stated that the case study presented in this thesis may be best described as an 'exploratory single case study' (Yin, 1984). The 3 initial aims/parameters of the study were extremely broad at the outset of the project but became quickly refined into shifting, yet focused, points of inquiry as soon as the programme of fieldwork was underway. Such an approach, though an "*all-or-nothing risk*" (Yin, 2009: 58) was ultimately highly rewarding. The advantage of "*resisting the generation of hypotheses too early in a case study*" as advised by authors such as Nisbet & Watt (1984: 79) and Cohen *et al* (2011: 18-219);

“Researchers [should] generate rather than test hypotheses....theory should not precede research but follow it”- ultimately allowed me to gather data very openly in a way which allowed me to constantly challenge my own assumptions in relation to Sean’s apparent limitations, drawing upon what Macfarlane (2010: 24) calls “*epistemological and personal reflexivity*.” A key advantage that a qualitative, multi-method, case study approach holds for practicing teachers over other methods is the inherent “*opportunity to learn and grow as a professional*”, by providing a “*personal experience that supports new insights and ideas*” (Miller & Kantrov, 1998: vii).

In the case study presented in this thesis, 4 key methods of data collection were employed during the course of the fieldwork. These were 1) field notes, 2) interviews, 3) photographs, and 4) video footage. Table 6 below details what particular methods of data collection were employed on each of the 31 days of fieldwork.

Table 6- Overview of application of data collection methods (NF=Field notes PHO=Photographs VID=Video footage)

Day	Date	FN	PHO	VID	Interviewed activity leaders
1	08/06				
2	09/06				
3	10/06				
4	11/06				
5	14/06				
6	15/06				Mr. Brendan Cronin (Yachting AL)
7	16/06				Ms. Joanne Lenihen (Swimming AL)
8	17/06				Mr. Jason Carey (Horse Riding AL)
9	18/06				
10	21/06				
11	22/06				
12	23/06				
13	01/07				
14	02/07				
15	05/07				
16	06/07				Mr. Gavin Daly (Motorsport AL)
17	07/07				
18	08/07				
19	09/07				
20	12/07				
21	13/07				
22	14/07				
23	20/07				
24	21/07				

25	22/07				
26	23/07				Mr. Corin M. Armstrong (Tae Kwon Do AL)
27	26/07				
28	27/07				
29	28/07				Mr. Pat Falvey (Mountaineering AL)
30	29/07				
31	30/07				

In addition to the methods of data collection detailed above, a number of additional documentary materials were consulted in the latter stages of data analysis and triangulation; namely drawing and writing samples that were produced by Sean both preceding and following the period of fieldwork. These included the aforementioned hundreds of drawings and associated written dialogues that he had created from as early back as February 2009 (in ‘piecing together’ of the ‘Aron Narratives’- appendix G), as well as extracts of his personal writing, 2 of which he produced in September 2010 and February 2011 (which are presented in chapter 5).

Further to this, chapters 4 and 5 make references to 5 keynote addresses which were made upon the occasion of Sean’s ‘awards night’ which was held in the school on the evening of December 14th 2010. Upon this occasion Sean presented a cheque for 725 Euro to a representative from the ‘Chernobyl Children’s International’ charity- money he had raised (through his charity climb on day 28 of the fieldwork for the Vesnova Children’s Orphanage in Belarus), after which 5 keynote speakers (outlined in table 7 below) offered valuable contributions and insights into what had been the period of fieldwork; insights and unique perspectives which added a further rich layer to the process of triangulating the data.

“*Triangulation in multi-method research*”, as Denzin & Lincoln (2008: 7-8) explain, “*is essentially an attempt to secure as in-depth an understanding of a phenomenon as possible...through multiple, refracted realities.*” Such a depth of understanding- relating to the human and contextual dynamics that underpinned the period of fieldwork- strongly emerged during the course of the evening in question, from a number of differently and uniquely positioned perspectives.

Table 7- Key Speakers at Sean’s Award’s night, December 14th 2010

No.	Speaker	Speakers profession and/or background
1	Mr. Sean Cronin	Chernobyl Children’s Project fundraiser
2	Dr. Noreen Cronin	Sean’s mother and medical nutritionist
3	Mr. Brendan Murphy	Actor Cillian Murphy’s father and former SEN School Inspector
4	Mr. Pat Falvey	Professional mountaineer, explorer & motivational speaker
5	Mr. Joe O’Leary	My father, professional mountaineer and post-primary school teacher

However, to return to the 4 key methods of data collection outlined in table 6, I will present a short discussion of these methods by considering, in the first instance, the role that field notes played in the data collection process.

Field notes

Typically, according to Woods (1986: 44), “*field notes consist of jottings [taken] during the day sufficient to jog the memory on what one has seen and wishes to record, with more extensive notes being written up later.*” As table 6 illustrates, field notes were taken on all 31 days of fieldwork. Passing observations and thoughts in relation to Sean’s behaviour and general demeanor, as well as many unexpected spontaneous conversations that took place between Sean and I (very often during our car journeys to and from various activities), were recorded in raw format on digital Dictaphone on a day-to-day basis (as were all interviews which will be discussed shortly). Field notes for each day were then typed up each evening/night following the activities (on average 2-3 pages per day). The exception to this were 3 days when activities carried on late into the evening; day 17 (‘Westlife’ concert), day 28 (assent of ‘Carrauntoohil’) and day 29 (‘Mamma Mia’ concert). Field notes for those days were typed up the morning after the activities. “*Record the notes as quickly as possible after the observation*” Cohen *et al* (2011: 300) advise social researchers, “*since the quantity of information forgotten is very slight over a short period of time but accelerates quickly as time passes.*”

In the original typed field notes when unexpected conversations took place between Sean and I, those conversations were written up in full. The exact wording of the conversations was recorded in order to preserve their authenticity as evidence. Many extracts from those conversations appear throughout the course of chapter 4 and the honesty of those

conversations, I suggest, adds to the richness of the overall text. As Woods (1986: 45) adds, *“the main aim must always be to record as full and faithful an account of the day’s observations as possible, for the whole research depends upon the strength and accuracy of this material.”* The remainder of the field notes consisted of often scattered and disconnected observations, emerging questions and self-reflections, in relation to Sean’s world of pretence, his engagement with fieldwork participants and I, and my own shifting perceptions of events as they unfolded.

A key advantage of placing an important emphasis upon collecting and typing what were often very lengthy field notes very quickly after events unfolded (despite it being an often very tiring process) was that it allowed the ‘story’ to emerge and unfold chronologically. As I will describe subsequently in this chapter, in analyzing and presenting the data, it was necessary to present a ‘thematic reconstruction of events’ as opposed to a strictly chronological account of events. Yet a rich chronological account of events was essential in the first instance to allow a number of ‘plots’ and ‘sub-plots’ to reveal themselves (which gave rise to key turning points in the study) which still remained central to the final written-up case study despite its thematic reconstruction. Colyar & Holley (2010: 74-76) describe plot as the *“chain of causation which dictates that story events are somehow linked and that they are therefore to be depicted in relation to each other....through the plot, authors provide a sequence of time and order to the story.”* In writing chapter 4, it was important to analyze and present events thematically, yet it was likewise important to preserve some aspects of chronology in framing the narrative in order to address what Denzin & Lincoln (2008) term the ‘situated’ and ‘relational’ structures of the ethnographic experience.

The crucial role that the collection, interpretation, and re-interpretation of field notes played throughout the course of the fieldwork, as well as during the data analysis phases (a sample of the 4 levels of field note analysis is provided in appendix D), is subsequently discussed in depth in relation to the ‘the analysis of narratives’. However, it is important to further note that a key advantage of collecting data through the medium of field notes lay (like the other methods of data collection) in its unobtrusiveness. As Woods (1986: 44) concludes, *“it may not be convenient or desirable to take notes openly. Especially if a participant, there may be no time, and it may actually interfere with the interaction.”* Field notes could be written up (by simultaneously reviewing photographs, film footage and Dictaphone recordings relating to events and activities) *after the event itself*, and thus I was free to fully commit to (and

focus my full attention upon) acting as both a participant and observer in activities, and to switch between both roles as circumstances dictated.

The role of interviews

Interviewing is one of the most common and powerful ways in which we try to understand fellow humans (Fontana & Frey, 2008). In total, 6 key semi-structured interviews (full interview transcripts are included in appendices H, I, J, K, L & M) were carried out with 5 key activity leaders. Three of the 5 shorter interviews, with Gavin Daly (motorsport) and Jason Carey (horse riding), Joanne Lenihen (swimming) were conducted ‘on site’, directly following the associated activities. The 3 remaining interviews; with Pat Falvey (mountaineering), Brendan Cronin (yachting), and Corin Morgan-Armstrong (Tae Kwon Do) were conducted in a separate location from where the activity itself had taken place. In addition to the interviews that were conducted during the course of the fieldwork itself, chapter 4 makes reference to 7 additional interviews and meetings (that involved Sean, his parents, and his extended family) that were conducted both prior and subsequent to the 31 day period of fieldwork. These interviews/meetings are listed in table 8 below.

Table 8- Pre & post fieldwork interviews and meetings

<i>Cited pre-field work interview</i>		
<i>Date</i>	<i>Location</i>	<i>Participants</i>
14/04/2010	School office	Sean Cronin & Loretta O’Sullivan (SNA)
<i>Cited post-field work interviews</i>		
<i>Date</i>	<i>Location</i>	<i>Participants</i>
30/07/2010	Cronin family home	John & Noreen Cronin
29/03/2011	School office	John & Noreen Cronin
<i>Cited post-field work meetings</i>		
<i>Date</i>	<i>Location</i>	<i>Participants</i>
17/03/2011	School office	Sean Cronin, John Cronin, Noreen Cronin
18/06/2011	Cronin family home	John & Noreen Cronin & their extended family
20/07/2011	Cronin family home	Noreen Cronin
03/09/2011	Cronin family home	John & Noreen Cronin

It is crucial to note, however, that in addition to the interviews referred to above there were other less formal, but equally important *conversations* / ‘unstructured interviews’- that played a vital role in the wider process of *communication* throughout the course of the study.

Fontana & Frey (2008: 116) contrast the ‘scientific’ / ‘traditional’ approach towards interviewing, which concentrates upon the language of scientific neutrality, with an approach

they term ‘empathetic interviewing’; an ‘active’, collaborative approach towards interviewing in which “*social scientists realise that they need to interact as persons with [their] interviewees and acknowledge that they are doing so.*” The authors suggest that unstructured interviews can provide greater breadth than structured/semi-structured interviews by engaging with the ‘thoughts and feelings’ of the respondents in question. Whilst structured interviews aim to capture precise data of a ‘codable’ nature in order to explain behaviour within pre-established categories, unstructured interviews “*attempt to understand the complex behaviour of members of society without imposing any priori categorisation that may limit the field of inquiry*” (ibid: 2008: 118).

As previously mentioned, involving Sean’s parents as active participants in the project necessitated an ongoing ‘dialogue’ that was fundamental to the project’s development. There were the countless ‘cups of coffee’ and invites to dinner, for instance, which often amounted to the most deeply moving, thought provoking conversations with Sean’s parents, that while not conducted as formal interviews (which would, in fact, have been inappropriate), led to the most crucial of insights into the world of *their child*, a young man whose welfare and well-being had been entrusted so positively into my hands. Fontana & Frey (2008: 144) conclude that unstructured interviews should be seen as “*negotiated accomplishments of both interviewers and respondents that are shaped by the contexts and situations in which they take place.*” Woods (1986: 67) further adds that the word ‘interview’ may sometimes be a rather inappropriate term for what are in actuality “*conversations that take place in the ordinary course of events, indicating a more open, democratic, two-way, informal, free-flowing process wherein people can be ‘themselves’ and not feel bound by roles.*” The day-to-day conversations with Sean’s parents were *essential* in helping me to gauge how well Sean was responding to the fieldwork activities as they progressed, leading to a truly ‘shared agenda’, one that allowed us- jointly- to raise the bar of possibility for Sean.

The role of audio-visual methods

Visual media are the ‘commonplace stuff’ of ethnographic and anthropological educational research (Cohen *et al*, 2011). While “*rather than standing on their own, visual data are only one element in triangulated data*” (Cohen *et al*, 2011: 529), visual and audio-visual data may nonetheless contribute- this study suggests- a highly rich, and powerfully emotive element to the collection and dissemination of data in case study research. Such data may “*catch the*

texture, the mood, the atmosphere, the 'feel' of real life and different places, emotions and flesh-and-blood drama" (ibid: 530). Essentially, the power of audio-visual media is to "tell a story [perhaps] focusing upon critical incidents, turning points and key events" (ibid: 531).

Over the course of the fieldwork, photographs were taken on 16 (51.6%) of the 31 days, while additional video footage was taken on 21 (67.7%) days. Cohen *et al.*, (2011: 530-531) note that in social research "video materials can catch both the everyday routines and natural social situations of participants, and also special events.... for instance a DVD of a celebration of commemorative activity." Photographs and film served both of these purposes over the course of the study. In the first instance, the 'raw data' (film and stills) provided me with an 'audio-visual record' of the fieldwork which was extremely useful as a reference point, both in the early phases of writing up my field notes after each day's activities, as well as throughout the 2 latter stages of 'narrative analysis' (which will be described subsequently). In the second instance, it was possible, using audio-visual data, to create 3 commemorative DVDs- 1) 'Sean's Victory' (30 mins), 2) 'Sean's Journey' (12 mins), and 'Sean's Awards Night' (60 mins) following the period of fieldwork. The first and second of these productions are audio-visual montages (of film and stills) which 'tell the story' of specific activities that Sean undertook throughout the course of the fieldwork, set to a 'Westlife' soundtrack (composed of what became Sean's favourite 'Westlife' songs). The first production, 'Sean's Victory' tells the story of his ascent of Carrauntoohil, and was aired publicly for over invited 100 guests upon the occasion of his aforementioned 'awards night'.²⁷

The creation of these DVDs was important for a number of reasons. As I will discuss in the concluding sections of chapter 4, a concern that some fieldwork participants expressed was that Sean may not be able to retain or 'hold onto' his achievements, or give himself adequate credit for them. This concern, more than anything else, was the rationale behind the production of the DVDs. As chapter 5 will further discuss (in relation to the 'performance text'), the DVDs were produced with the intention of helping Sean to internalise and positively retain his role in the fieldwork activities. In one way the DVD productions may be said to constitute an experimental approach towards the production of 'life stories', which is

²⁷ The second DVD captures the dynamics of the interactions between Sean and the associated activity participants in relation to the activities of yachting, motorsport, golfing, Tae Kwon Do, and the 'Westlife' concert, as well as one of our own conversations in a relaxed cafe environment. The third is an edited recording of the 'awards night' celebration.

common practice within the fields of criminal justice and disability studies.²⁸ Aspinall (2010) explains that, traditionally, the most common way for life stories to be captured has been through a face-to-face interview with a person with a learning disability. While some people with learning disabilities have written their own 'life stories', Aspinall (2010) concedes that for many people it is not possible to 'tell' their life story without help. Thus, she urges educators to be creative both in the way that the story is told, as well as in the medium used to tell it, suggesting that multimedia approaches in particular can create 'a very powerful arrangement of memories'.

However, it is only appropriate to acknowledge that the use of photographic and audio-visual methods in disability studies has been criticised by some commentators. Hewey (1992), for instance, has argued that most of the pictures of disabled people that surround us focus upon the impairment or disfigurement of the person, while Vlachou (1995) warns that such images may be constructed in such a way as to arouse feelings of pity. It is true, as Vlachou (1995) contends, that the images we produce may carry ideological messages which, cumulatively, help to shape people's ideas, values and attitudes. However, I would like to think that Sean's DVD productions have served primarily as vehicles of empowerment for him. There is no mention of the word 'autism' in any of the 3 DVD productions (never was the word 'autism' even mentioned on the 'awards night'). Nonetheless, the presentation of this form of data, on the awards night in particular, revealed itself to be a remarkably emotive tool, *which does not try to tell people what autism is or isn't*- that's not the point of it- but rather to present a *person* to them, and to allow them to make their own inferences and draw their own conclusions.

Perhaps a final criticism that could be made in relation to the DVD productions of Sean's experiences and achievements (from a traditional participatory perspective), is that they were created *for* Sean and not *with* Sean. Aspinall (2010) argues that the 'life story' should be created in collaboration with the individual, going so far as to say that the subject of the 'life story' should make all of the choices and decisions in its creation. Unfortunately, this was simply not possible to do with Sean at the time. As chapter 4 reveals, Sean could not- until

²⁸ The creation of life stories has been used in the criminal justice system to discover whether any events in prisoners lives had led them to their criminal activities, while in the field of learning disability studies, they have traditionally been used to help people with learning disabilities to put life events into a chronological order (Aspinall, 2010).

the occasion of his awards night- bring himself to look at video footage of himself (particularly footage in which he was speaking). Thus to attempt to involve him in the production of his DVDs, at this early stage, would have caused him more distress than pride. Thus, the objective was, through the production of his DVDs, to present him with an uncompromisingly positive picture of himself.

Analysis of the data

Introduction- the framework of narrative inquiry

While researchers who adopt an objectivist/positivist approach to the social world, and who consequently adopt 'structured approaches' to data collection, drawing upon methods such as surveys and questionnaires, may produce data that while being perhaps 'weak in reality', it is nonetheless data that may be 'susceptible to ready organisation'. Qualitative researchers, on the other hand, while being free to be more creative in their choice of methods, often end up with an enormous amount of data, while being 'strong in reality', may be notoriously difficult to organise (Cohen *et al*, 2011). This is a reality that I immediately encountered upon the completion of the fieldwork activities. Analysing the data demanded a synthesis- a 'tying together'- of a multiplicity of constantly shifting points of view and angles of vision, collected through multiple methods; further undercut by ever-shifting human emotions that emerged across different 'sites of experience', over a 2 month period of time, and beyond.

"Qualitative researchers", Colyar & Holley (2010: 70) tell us, "have long struggled with the question of how to represent social reality through the academic text....while researchers historically have been bound by a limited template in terms of scholarly writing, recent decades have seen the development of innovative textual structures and alternative forms of representation." One of these is termed 'narrative inquiry' a form of inquiry that analyses narrative in its many forms, and uses a narrative approach for interpretive purposes. Considering the complexity and diversity of the data to be analysed and presented, the analytic approach of narrative inquiry was perhaps the only approach that could offer a framework that could not just 'handle the data', but also preserve its richness, its honesty, and its scope to 'speak for itself'.

Because, as previously discussed, in social research it is often impossible to separate a phenomenon's variables from their context (Yin, 1984), as it was in this case, it was therefore necessary to find a framework, or an approach, that may preserve the complexity of the human experience. Narrative inquiry was ideally suited to this task because it is, as Connelly & Clandinin (1990:7) maintain, essentially "*the study of the ways humans experience the world*". 'Narrative inquiry is, in the words of Polkinghorne (1995:7), "*the linguistic form that preserves the complexity of human action with its interrelationship of temporal sequence, human motivation, chance happenings, and changing interpersonal and environmental contexts.*" The framework of 'narrative inquiry' thus favours 'thick descriptions' over reductionism. 'Thick description' is a term borrowed from anthropology that refers to the "*complete, literal description of the incident or entity being investigated*" (Merriam, 1988: 11). Moreover, narrative inquiry allows the researcher to blend a description of events with an analysis of them (Cohen *et al*, 2011) which was precisely the approach taken in the writing of chapter 4.

'Narrative analysis'

In approaching the discipline of 'narrative inquiry', Smeyers & Verhesschen (2001) suggest a useful distinction which may be made between what are termed 'narrative analysis' and the 'analysis of narratives'. The former, *narrative analysis*, is very closely related to what Bruner (1986) calls 'narrative cognition' and focuses, as Smeyers & Verhesschen (2001) explain, upon the more particular aspects of each human act. Within this study, for instance, I investigate how Sean engages with and learns from a multiplicity of external narratives (such as DVDs, video games and comics), how he constructs his own narratives, how he draws upon narrative to express himself, as well as how he learned to draw upon the beauty of musical narrative and, as a consequence, moved towards communication on an extraordinarily profound level with both himself- (the interpersonal narrative, the narrative of self) and with others (the intrapersonal narrative; the shared emotional engagement in narrative experiences).

The 'analysis of narratives' and its application to the study

The *analysis of narratives*, on the other hand, implies an engagement with narrative in its broader sense. Within the context of the case study presented in this thesis, the 'analysis of

narratives' provided a connective tapestry across which a *multiplicity of narratives* could be tied together within a coherent written framework, including Sean's 'internal narratives' as well as the 'narratives of everyday experience'. The presentation of the 31 days of fieldwork- as it is written- attempts to stay as true as possible to the story of what took place by presenting a thematic reconstruction of events. As Smeyers & Verhesschen (2001) explain in the *analysis of narratives* one looks for common features in different cases in order to define them as belonging to a broader category; the narratives themselves form the research data and by pointing to features that different narratives have in common, one may begin to construct conceptual frameworks by looking for common themes.

Through a process of narrative analysis (incorporating field notes, interview data, and speeches made on 14/12/2010) I eventually arrived at and presented the data in chapter 4 under 9 broad thematic headings, each encasing a number of interconnected themes and sub-themes. The nine broad thematic headings are:

1. Understanding narrative processing.
2. The formation of sustainable relationships.
3. Personality and self-esteem.
4. The child-adult issue.
5. Choice, purpose and control.
6. The 'transformative effect'.
7. The assessment of progress.
8. Facing challenge.
9. Confronting challenge.

The following description of the two stages of narrative analysis is intended to explain (albeit somewhat mechanically) how I eventually arrived at the 9 themes above. Table 9 is included to allow the reader to see, at a glance, what sub-themes emerged under the wider themes and precisely how the data were triangulated.

Stages of narrative analysis

The first stage of narrative analysis incorporated 4 levels of analysis. The second stage incorporated 3 levels of analysis. (A sample of the 4 *stage 1* levels of analysis is presented in appendix D [for day 1 of the fieldwork]).

Stage 1 of my analysis of the data (August-December 2010) involved a linear/chronological engagement with the data. Specifically this involved:

1. A type up of all digitally recorded field notes for the 31 days (done during the fieldwork), as well as interviews that were conducted previously to and during the course of the fieldwork (done after the fieldwork took place) to reveal the 'raw data'.
2. The reduction of each set of typed field notes to a number of focused observations/further points of inquiry (average 10 points per day).
3. Collapsing closely related exploratory findings/points of inquiry into a reduced number of emergent points of discussion; critical reflection upon each point encompassing my wider contextual experience of Sean (average 6-7 points of inquiry/discussion).
4. Analysing stage 3 points of inquiry/discussion for each day under a number of emerging thematic headings (average 4-5 for each day), incorporating interview data, culminating in an initial 30,000 word chronological analysis of the study. (Corresponding with stage 1 data analysis was the production of 'Sean's Victory' DVD)

The second phase of data analysis (January-September 2011) involved a re-structuring (of all) and re-interpretation (of some) of the data (this incorporated the 6 post field interviews/meetings with Sean, his parents and members of his wider family) in order to analyse and present the data in a non-chronological thematic format. Arriving at the final 9 structural themes listed above involved 3 further sub-levels of narrative analysis.

1. Revisiting the written narrative analysis for each day (still chronological) and again (like stage 1, level 2) reducing each day into a number of more focused and specific points of analysis (total 140 [sometimes overlapping] points of analysis- see appendix E).
2. Grouping and coding (by day) these points of analysis under 29 further emerging themes in a non-chronological format (see appendix F).

3. Grouping these 29 themes (now sub-themes) under the final 9 themes/headings to frame the analysis, and mapping the precise days (stage 1, level 4 field notes) and sections from the interview data (including pre-fieldwork, post-fieldwork interviews, as well as speeches recorded on 14/12/2010) as a guide towards writing the final non-chronological analysis/discussion in chapter 4. (Corresponding with stage 2 data analysis was the production of the ‘Award’s Night’ DVD, and finally ‘Sean’s Journey’ DVD)

Table 9- Triangulation of the data (FN= field notes)

Understanding narrative processing			
Theme 1: Memory	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Visual	1	Not applicable	
Phonographic	16		
Memory & communication	1		
Theme 2: Dynamics	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Literal interpretation	25		
Sense of personal complicity		Sean Cronin	14/04/08
Infiniteness & quest for positive endpoints	3, 9, 11	John Cronin	22/06/11
Theme 3: Child versus adult	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Child narratives- accessibility & aesthetics	3, 12, 13	Not applicable	
Adult narratives- comprehension	9		
Theme 4: Narrative and ‘pretending’	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Mechanics & complexity	6, 16		
Pretending and creativity	15, 6		
Pretending, self-esteem & communication		Sean Cronin	14/04/08
Theme 5: Narratives	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Internalisation of narratives	3	Not applicable	
Social expression of narrative interests	23		
Theme 6: Musical narrative	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
The development of non-visual pretence	13	Not applicable	
Musical narrative & emotional engagement	13		
Musical narrative in a social context	17		
Musical narrative and human connection	17		
The formation of sustainable relationships			
Theme 1: Building a social circle	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
The process of investigation	3, 11,12	Not applicable	
The mechanics of linking characters & people	12, 13, 25, 28		
Developing friendships	14, 25, 26		

Theme 2: Maintaining the social circle	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Recognising opportunities for new friendships	4	Brendan Murphy	14/12/2010
The role of judgement versus acceptance	4		
Reading acceptance and rejection	4, 25		
Personality and self-esteem			
Theme 1: Sean's commitment to 'good'	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
The power of personality	1	Not applicable	
Empathy for others	19		
Theme 2: Self-concept and self-esteem	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Low self-concept & esteem	1, 2, 14	J & N Cronin	30/07/2010
Sibling rivalry	18, 22, 27, 28		
Developing sibling relationships	3,28		
The child-adult issue			
Theme 1: The child versus the adult	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
The child in Sean	14, 15	John Cronin	20/07/2011
The adult in Sean	9, 18		
Theme 2: Adult control, adult respect & performance outcomes	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Evidence of negative outcomes	7, 8	Brendan Cronin 14/06/2010 Gavin Daly 06/07/2010 Gavin Daly 06/07/2010 C.M Armstrong 26/07/2010 C.M Armstrong 26/07/2010	
Evidence of positive outcomes	5, 16, 29		
The development of adult relationships	15		
Control and opportunity	5		
Control and the regulation of time	5, 16		
Control and global attention	5, 16		
Respect & the nature of knowledge	26		
Challenging my own assumptions	5, 14, 16, 26		
Choice purpose & control			
Theme: Choice, purpose & control	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Lack of confidence in making choices	4, 14, 23	J & N Cronin Noreen Cronin	30/07/2010 20/07/2011
Outcomes of encouraging choice	10, 20		
The importance of purpose	2, 4, 19, 20		
The 'Transformative Effect'			
Theme 1: Building a planning network	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Creating a sustainable planning network	21	PCP meeting	18/06/2011
Person centred planning			
Theme 2: The 'Transformative effect'	FN	Interviews/Speeches	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>

Conceptualising a ‘Transformative Effect’	8, 17	Jason Carey C.M Armstrong	17/06/2010 26/07/2010
Excitement and communication	9, 17		
Outcomes of sustained social experience	23, 24		
<i>The assessment of progress</i>			
<i>Theme 1: Reconceptualising assessment</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
The benefit of hindsight	14	Not applicable	
‘Milestone’ versus subliminal progress	5, 13, 16, 17, 29		
Social experience and social ‘conformity’	4, 9, 20		
<i>Theme 2: Increasing social independence</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Evaluating the risks	13	J & N Cronin	18/06/2011
Exploring the possibilities	13, 31	J & N Cronin	18/06/2011
<i>Facing challenge</i>			
<i>Theme 1: The ‘autistic’ Sean</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Hypochondria	8	Jason Carey	17/06/2010
Fear of death	4, 15, 19	Sean, Noreen & John Cronin	17/03/2011
Physical difficulties	25	Noreen Cronin	14/12/2010
Traditional dislike of the outdoors			
<i>Theme 2: The person Sean</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-theme</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Physical strengths	23	C.M Armstrong	26/07/2010
<i>Theme 3: Implications</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Approaching the regulation of time	23	C.M Armstrong	26/07/2010
Harnessing optimism, motivation & trust	10, 13	Brendan Murphy	14/12/2010
<i>Confronting challenge- The ascent of Carrauntoohil</i>			
<i>Theme: The person versus the disability</i>	<i>FN</i>	<i>Interviews/Speeches</i>	
<i>Sub-themes</i>	<i>Days</i>	<i>Person</i>	<i>Date</i>
Safety considerations	29	Pat Falvey	June 2010
Balancing data collection with safety	29		
Challenge & risk versus focused ambition	29	Pat Falvey	28/07/2010
The triumph of the person over the disability	29	Pat Falvey	28/07/2010
		Pat Falvey	14/12/2010
		Joe O’Leary	14/12/1010

Using writing as a means of analysis

As the above description of the 2 phases of narrative analysis alludes to, the process was an extremely lengthy affair, lasting for approximately 13 months. Yin (2009: 143) makes the point that the analysis of data generated in case study research may, due to its sheer

complexity, need to be a lengthy ‘iterative process’, within which “*the researcher has to go back through the data several times to ensure that all the data fit the interpretations given or conclusions drawn.*” Writing was my means of doing this; of exploring, dissecting, deconstructing, reconstructing, reflecting upon, re-reflecting upon, and ‘feeling’ the data as it emerged. Writing is a method of inquiry that, as Denzin & Lincoln (2008: 26) put it, “*moves through successive stages of self-reflection....as a series of written representations, the field-worker’s texts flow from the field experience, through intermediate works, to later work, and finally to the research text, which is a public presentation of the ethnographic and narrative experience....thus fieldwork and writing blur into one another.*”

During those days in which I became more fully personally immersed in the narrative itself (as alluded to previously, a ‘player in the action’), I became very much ‘part of’ the story I was about to tell. In ‘telling the story’, in chapter 4, I am conscious of the shift that was made from traditional ethnography to that of ‘autoethnography’, a process of “*writing the self into the ethnographic narrative*” (Denzin & Lincoln, 2008: 643). As Connelly & Clandinin (1990:4) put it, in autoethnography “*the two narratives of participant and researcher become, in part, a shared narrative construction and reconstruction through the inquiry.*” Addressing, or even trying to conceptualise, my own positionality within the entirety of the research experience; from that of Sean’s teacher preceding the fieldwork, to that of friend in the course of the fieldwork, from the normal pupil-teacher relationship with Sean’s parents before the research project began, to becoming a family friend (with further bonds of friendship being forged between my own wider family and Sean’s family) during the course of the research experience- and then having to revert to my previous role- was an extremely emotional and confusing affair. In the field notes for day 31, again using writing as a means to process and to think, I reflected;

“After I dropped Sean home, we [John, Noreen and I] sat down and reviewed some of the ‘raw’ video footage that I had collected over 31 days. In the only official ‘interview’ that I conducted with Sean’s parents during the course of the fieldwork, after 5 minutes I terminated the ‘interview’, switched the Dictaphone off and simply sat back and shared with Sean’s parents glimpses of the remarkable achievements that Sean had accomplished over the 2-month period. We laughed, we cried, and we wondered why on earth we had underestimated him for so long. Then I left- heartbroken. Heartbroken to leave behind a family I had grown to love. Heartbroken to return to a system of education that I now knew

was inherently underperforming. I had seen what was possible when the restrictions, the ‘ties and knots’ of ‘systems’ of education were for a brief- but wonderful- time unravelled, when the person was placed at the centre of the process of education, when education became a reciprocal, mutual process directed not towards changing the person, but changing itself in light of the beauty of the uniqueness of the human subject.”

Considering the power of the emotions underpinning the fieldwork experience, particularly in its latter stages, it was impossible for me to really position myself within the narrative until a threshold of time has passed: time I spent *writing* as a means of stimulating thought and reflection. According to Cohen *et al* (2011), narrative is a ‘human meaning-making tool’, the process by which individuals explore and later explain their experiences. Writing was my means of exploring, and constantly re-exploring those experiences. Thus, like St. Pierre, “*I used writing as a method of data analysis by using writing to think; that is, I wrote my way into particular spaces I could not have occupied by sorting data with a computer programme or by analytic induction. This was a rhizomatic work in which I made accidental and fortuitous connections I could not foresee or control*” (Richardson & St. Pierre, 2010: 488). Only through writing could I, as Pollard (1985) advises social researchers to do, ‘enter into a public debate’ with myself in order to elicit the basis of my own perceptions.

This ‘public debate’ may be said to amount to ‘a critical phenomenological analysis of the self’ (Robinson, 1974). Clough (2002: 88) describes phenomenology as “*a systematic attempt to recapitulate the events of meaning.*” Essentially, in phenomenology the reality which the researcher seeks to uncover and expose lies in the *perception* of an event rather than in the event itself. In phenomenology, the emphasis- as Porter & Lacey (2005) explain- ultimately lies with the subjective experience of events. From a phenomenological perspective “*research is a combination of both experience and reasoning....one can only impute meaning to [experiences] retrospectively, by a process of turning back on oneself and looking at what has been going on....meaning can only be accounted for in this way by the concept of reflexivity*” (Cohen *et al*, 2011: 4-19).

As Smeyers & Verhesschen (2001) put it, ultimately, narrative analysis has all the characteristics of what is usually called an ‘interpretation’. Themes which emerged in the course of the analysis, such as- for instance- ‘transformative moments’, emerged only after each and every event, as captured through field notes, interviews and audio-visual data, had

been revisited and re-explored from every possible angle. In a great many instances my perceptions of what data suggested and represented, shifted somewhat when re-visited in terms of the entirety of the experience. It was essentially like- through the tapestry of writing- being able to see the fully assembled jigsaw when previously my perception had been limited to only one piece or section of the puzzle.

Validity and transferability of the study

As Cohen *et al* (2011: 293) note, “*like other research methods, case study has to demonstrate reliability and validity.*” In the following section I argue that this study fulfils the criteria for reliability and validity based upon; 1) its exploration of multiple methods in the overall research design, 2) by linking theoretical ideas in autism studies in new ways, and 3) its potential accessibility to both teachers and parents of young people with autism, as well as- perhaps even- those with autism themselves.

‘Construct validity’ refers to a researcher’s employment of accepted definitions and constructions of concepts and terms in his/her related field (Cohen *et al* 2011). As was alluded to in chapter 2, this study seeks not to reject the dominant theories in autism research, but rather to extend them in new directions and link them in new ways. In chapter 5, I will discuss how the findings of the case study presented in the forthcoming chapter may be applied to extending and, in some circumstances, reconceptualising of some of the dominant theories in autism studies.

‘Concurrent validity’, meanwhile, refers to the use of multiple sources and kinds of evidence to address research questions, while ‘convergent validity’ refers to the triangulation of data (Cohen *et al*, 2011). As Yin (2009: 122) notes “*diverse data provide the evidential ‘chain of evidence’ that gives credibility, reliability and validity to the case study.*” Thus, this chapter has provided an overview of the use of multiple methods of data collection employed in the study, as well as how the associated data was triangulated. Similarly, chapter 2 referred to both autism-specific, as well as non-autism-specific literature, consulted in the literature review phase, across multiple fields of inquiry including anthropology, psychology, neuropsychology, neurology, as well as the ‘hidden voices’ of those in the autism community. One purpose of chapter 5 will be to synthesise those various understandings of

autism, and based upon the findings of the research, revisit them, and re-‘view’ them- through the ‘lens’ of the research findings.

In chapter 1, I stated that while it is not an intention of this study to produce ‘generalizable’ findings in relation to autism as a condition (in a deductive fashion), this study does nonetheless aspire towards producing ‘transferable’ insights based upon an exploration and presentation of the phenomenon of autism in an inductive manner. Whilst the positivist paradigm is organized around a normative epistemology, which contends that ‘normal’ is what is most representative in a larger population, and it is to that ‘normal’ population that generalizations are directed (Van Niekerk & Savin-Baden, 2010), this study contends that ‘difference’ and ‘uniqueness’ is what characterises people with autism- not their perceived deficits- and thus qualitative studies in autism research should resist the temptation of setting out intent upon producing ‘generalizable’ results. Yet, that it not to suggest that research findings in autism studies- even those as idiographic as a single case study- cannot produce insights that may invite new interpretations and perspectives of autism;- not about ‘what autism is’- but how it may be approached and understood in new ways when working with children and young people on the autism spectrum.

Yin (2009) defines ‘transferability’ (or what is sometimes called ‘comparability’) in case study research as the degree to which the results of qualitative case studies can be transferred to other contexts or settings. While the findings of this study may, it is hoped, indeed be transferable to other contexts and settings in working with young people with autism, it should be noted- however- that the study’s findings are not ‘context-specific’ which, perhaps somewhat paradoxically, may perhaps add to their ‘transferability’. The study’s findings are not located ‘within’ any one of the multiple contexts in which the fieldwork took place; rather they were generated *across* those contexts. Thus, rather than being limited to a specific context or contexts, the study’s findings are more applicable to a wider relational approach to working with young people with autism that places more emphasis upon *how* we engage with them as being *the* crucial ‘variable’ to consider, as opposed to *what* context-specific variables we need to account for or control in our dealings with them. Thus, some of the key findings of this study, for instance, relate to the importance of promoting *choice, control, challenge* and *celebration* in the lives of young people with autism. It is those *principles* that this study suggests may be transferable in a way that invites *people*, on the most fundamentally human

of levels, to consider in imagining new options and possibilities for young people with autism.

An important aspiration of this thesis, as mentioned in chapter 1, is that it may be accessible to a wide audience. Commentators such as Barton (1998), and Clough (1995), have argued strongly that traditional forms of educational research, particularly those that have tended to elevate method and instrumentation above personal values, have failed to affect wider change in the community. In presenting the analysis and discussion of the study in chapter 4, I have attempted- by deliberately adopting a rather free-flowing writing style- to convey, to the best of my ability, the shifting feelings and emotions which framed the study as it evolved. Studies with an “*identifiable moral purpose*”, Clough (2002: 82) contends, “*draw their appeal from the power of their language, the depth of their explanations, the relevance of their examples, and the credibility of their themes.*” In such studies, Denzin & Lincoln (2008: 33) maintain, “*terms such as credibility, transferability, dependability, and conformability replace the usual positivist criteria of internal and external validity, reliability, and objectivity.*”

Furthermore, as Cohen *et al* (2011) point out, while social science texts must respond to questions of reliability and validity, they must also speak to questions of ‘readability’. Thus, I have attempted to draw upon Clough’s (2002: 83) call to researchers to “*assemble, within their research craft, an honesty and integrity of language with which to express the moral positions (as well as the methodological justifications) of their inquiry*”, to make it more real, to imbue it with feeling, to preserve its purity and truth, and to allow experience to speak for itself. I have thus attempted, in presenting the study, to remain as ‘true as possible’ to events as they occurred and unfolded, but without sacrificing the ‘subjective experiences’ of the study’s many participants. While the reader may detect certain ‘hints of bias’ throughout chapter 4, chapter 5 will go on to suggest that such ‘bias’ may in fact be better understood and conceptualised as ‘advocacy’.

Approaching ethics

In the concluding section of this chapter I will discuss why I made the decision to include the real names of many of the project’s participants (and its supporters), as well as how I

addressed the issues of both ‘procedural’ and ‘trans-situational’ ethics in the period preceding the fieldwork activities.

Anonymity and confidentiality versus the ‘naming’ of individuals

According to Macfarlane (2010: 21), “*while it has become a default position that researchers from all disciplines must offer participants confidentiality and anonymity....research ‘subjects’ can be eager to tell their own friends and family about their participation in a piece of research.*” Point 25 of the ‘Ethical Guidelines for Educational Research’ states that “*confidential and anonymous treatment of participants’ data is considered the norm for the conduct of research.....unless participants or their guardians or responsible others, specifically and willingly waive that right..... Researchers must also recognize participants’ rights to be identified if they so wish*” (BERA, 2011).

Those people who are named in this study are named in accordance with their *fully expressed wish* to be named in the thesis. They are also named in acknowledgement of their invaluable contribution to this study. As previously discussed, an important aim of this case study is that it will be accessible (and therefore available) to a wide audience. Many of those who will most likely read this document will be the parents of children and teenagers on the autism spectrum in the local community. To fail to name and acknowledge the contribution of those who participated in the project, as well as Sean’s classmates and their parents- those who belong to the same community- would be to do them an enormous disservice, particularly again in light of their expressed excitement to be named in a study that may have some impact on a local level.

In relation to the DVD recording of Sean’s ‘awards night’, as well as the additional DVDs of Sean’s achievements, it was decided not to include these as appendices, but rather to grant ownership of those DVDs to Sean’s parents. It was also decided that they would not be included in the archived version of this thesis. As Cohen *et al* (2011: 533-534) note, “*ethics in visual research are less well developed than in numerical and text-based research.*” The ethically correct decision in relation to these audio-visual productions was to entrust the data to Sean’s parents’ hands, whom they can then consult with Sean himself in relation to what contexts they may be viewed within (e.g. with family and friends).

No local ASD service providers or schools (ABA nor TEACCH) referred to in study are named because a reader may be tempted to associate the critiques of autism-specific teaching methods and approaches (in chapter 2) with those schools and organisations themselves- which would be misleading. However, certain organisations and individuals that supported the project (such as ‘Westlife’, actor Cillain Murphy, Taoiseach Enda Kenny, ‘Chernobyl Children’s International’, and the City of Cork VEC) are named in acknowledgement of their tremendous contributions to the project. Likewise, Sean’s school where the ASD unit was developed is named in acknowledgement of its role in Sean’s education and the ‘centre of celebration’ that it became in the aftermath of Sean’s fieldwork achievements. The school deserves full credit and acknowledgement for its contribution to this project.

Approaching ‘voluntary informed consent’

In accordance with procedural ethics, Sean and his parents all signed consent forms in a pre-fieldwork meeting in my school office (14/04/ 2010). Signing these forms was just one component, however, of a much deeper consideration of the guiding ethical principles of the project. As previously mentioned, Sean’s parents placed a great deal of trust in my hands from the very outset of the project- to act in the best interests of their son. Being an exploratory project however, it was impossible to plan for every eventuality- but it *was* possible to *agree to work together*. We recognised that, as Macfarlane (2010: 19) puts it, “*the uncertainty and unpredictability of the research process means that real research ethics consist of facing moral challenges in the field*”, and we agreed to work together in that regard.

There is an important distinction to be made between ‘procedural ethics’, which is about satisfying the research ethics process, and ‘ethics in practice’ where the real challenges lie in making decisions in the field (Macfarlane, 2010: 22). These may be termed ‘transsituational ethics’ which, as Denzin & Lincoln (2008) explain, apply to the ‘human to human relationships’ and unpredictable eventualities inherent within the research act. As previously mentioned, the project was designed to be as much ‘for Sean’ as it was to be ‘about Sean’. It was agreed from the outset that if some findings were to emerge that may inform long-term-planning for Sean, well in good. However, if the fieldwork activities were to amount to nothing more than a ‘positive set of experiences’ for Sean, that would be a perfectly good

outcome. As Sean's father put it on the day in question, *"if we could get him to the stage that he likes going outside, that would be a result."*

We further agreed (in accordance with point 15 of the BERA ethical guidelines) that if Sean expressed a wish to withdraw from the project at any time, his wish would be fully respected. It should be noted that while Sean's parents ultimately 'consented' to the project on Sean's behalf (what Macfarlane [2010] terms the giving of consent 'by proxy') Sean was fully involved and informed in the consent process and signed his own individual consent form. In relation to 'voluntary informed consent', point 11 of the 'Ethical Guidelines for Educational Research' states that *"researchers must take the steps necessary to ensure that all participants in the research understand the process in which they are to be engaged."* In explaining to Sean what the project would involve, before he signed his consent form, Noreen put it to him that he would be *"spending the summer holidays doing activities with Steve,"* to which Sean, with his trademark 'wry smile', happily agreed.

CHAPTER 4- THE CASE STUDY- DISCUSSION AND ANALYSIS

“Ask not what disability the person has, but what person the disability has.”

-Oliver Sacks (1995: x)

Understanding narrative processing

Introducing narrative processing

In September 2008, when Sean first entered my programme, he instantly established himself as something of an enigma. On the one hand he had fleeting moments wherein he could launch into extremely lucid- albeit fragmented- conversations with me. Yet on the other hand he went through days in which he would remain self-isolated, closed off, happier within his own world of fantasy than in making contact with the outside world. He was the kind of child however that, no matter how difficult he was to reach, always hit you with a sense of charm, humanity and warmth that would constantly keep one searching for some way in.

One day, entirely at my wits ends, I just sat down with Sean. Verbal communication was a ‘non-starter’ at this point so I just handed him a blank piece of paper, and a pencil, and simply said *“Sean, draw for me what’s going on in your head.”* What Sean produced in response to this question, without saying a word (in late January 2009) came as a surprise to me, to say the least. Figure A (see appendix G) ‘Our Universe’, which he produced on the spot, was a mapping out of exactly how Sean perceived *his world* at the time; a multiplicity of universes composed of video games (the Mario, Sonic, Mortal Combat, Metal Gear & Star Wars universes), comics (the Marvel and DC universes), DVDs (Transformers universe), as well as a number of spiritual universes (the Spirit World, Heaven and Hell). Finally there was Sean’s ‘Private Universe’- one reserved only for Sean himself.

Today, with the ‘Aron narratives’ behind him, in almost every conversation that one will have with Sean, he will invariably ask questions in relation to the current *external narratives* that he is processing. Sean absorbs information (such as narratives relating to DVDs, comics and video games), processes this information (as seen through his drawings and his pretending), and then *communicates* this information to others through questions (*“Wasn’t it funny when...”*) (Field notes- day 1- 08/06/2010). Sometimes he will use a ‘question’ (which is

usually really a statement) to generate a conversation which interests him (Field notes- day 2-09/06/ 2010). This is facilitated in part, in my view, by the strength of Sean's narrative memory.

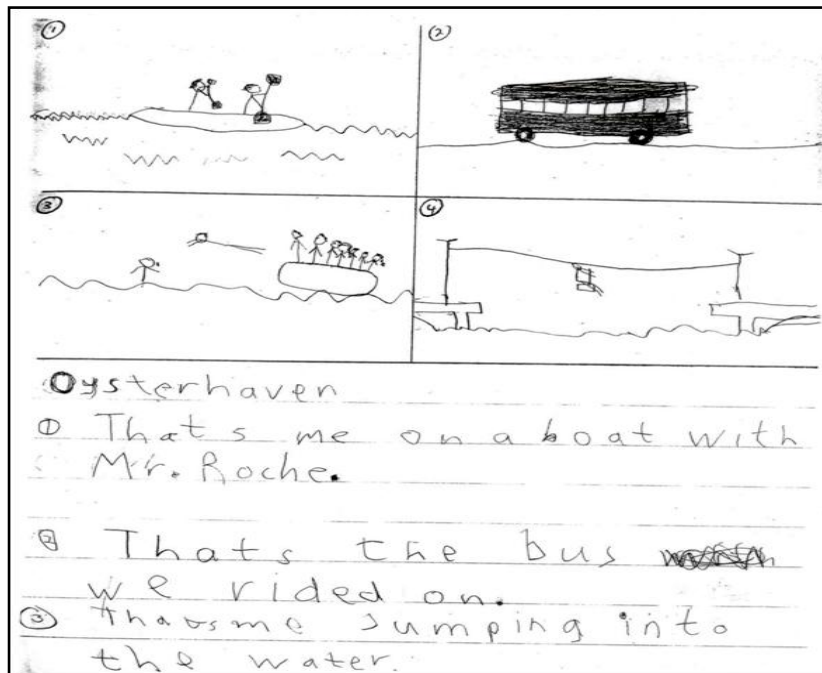
Narrative memory- the visual and phonographic

Two of Sean's strongest forms of memory are, I suggest, 1) visual and 2) phonographic. The strength of these 2 forms of memory reside for Sean, in my view, strongly within the wider domain of what may be described as 'narrative memory'.²⁹ Sean ultimately remembers best what he *sees* and what he *hears*, usually within the form of *story*.

I had a reasonably good idea, prior to the commencement of our fieldwork that Sean had a strong visual memory, evidenced by his ability to draw extremely accurate storyboards of his experiences. Figure T, for instance, is a storyboard relating to a class trip to Oysterhaven in May 2010. In fact, a conversation with Sean's mother before the fieldwork commenced suggested that Sean has always had a strong visual memory and used drawing as a means of communication with his parents when his speech was virtually non-existent. As a very young child (with little speech) he would arrive home from school and draw a storyboard of his day in school, present it to his parents, and say "*good day*".

²⁹ As I noted, on day 6, "*the fact that Sean's pretending on our return journey from Bishopstown to Douglas was in relation to the film the 'School of Rock', a film that he was very interested in over a year and a half previously, and definitely had not viewed for at least 6 months, suggested to me that Sean has the ability to retain narratives that appeal to him in his memory for very extended periods of time. This stands in stark contrast to other forms of memory (for instance relating as people he has met and places he has visited) which appear to be very weak*" (Field notes- day 6- 15/06/2010).

Figure T- Oysterhaven



Precisely because narrative plays such a crucial role in how Sean learns and subsequently communicates, throughout the course of our fieldwork I attempted to learn as much as I possibly could about what we might term the ‘mechanics’ of how Sean operates within the world of narrative and how, in addition to the acquisition of language, this plays itself out within the sphere of Sean’s love for ‘imagining’ and ‘pretending’ out narratives that he has seen.

Prior to our fieldwork, I had not grasped the extent to which Sean’s phonographic memory is just as strong, if not even more strong than his visual memory. On day 1 I noted that “*language from DVD narratives is carried into [Sean’s] own [personal] language in a very real way*” (Field notes- day 1- 08/06/2010). I subsequently noted on day 16 that Sean’s spontaneous performance of a lengthy monologue (*in Spanish*) from the movie ‘Click’ was very suggestive evidence of his very strong phonographic memory (Field notes- day 16- 06/07/2010).³⁰

³⁰ I noted on day 3 that “*Sean can draw very accurate pictures of places he has visited, including people, animals, and objects with which he has come into contact, in sequence, and with notable momentum*” (Field notes- day 3- 10/06/2010).

The communicative potential of narrative- shared emotional engagement and human connection

Not only does Sean acquire language from narratives but, I suggest, he also strongly *emotionally engages* in those narratives that appeal to him. Furthermore, and most importantly, he likes to *share* this emotion with those who watch DVDs with him.³¹ And this has very real implications for subsequent communication. Out on the boat on day 1, for instance, as we sailed around Kinsale harbour, our shared interest in ‘Father Ted’ allowed for shared, enjoyable and natural communication to take place. Importantly, it allowed Sean to *generate conversation-* (i.e.) he could strike up a conversation with me using ‘Father Ted’ as a reference point, where otherwise he would have been completely incapable of generating a conversation in the absence of a concrete, tangible narrative to generate it about. It also allowed me to *maintain conversation* with Sean³² (Field notes- day 1- 08/06/2010).

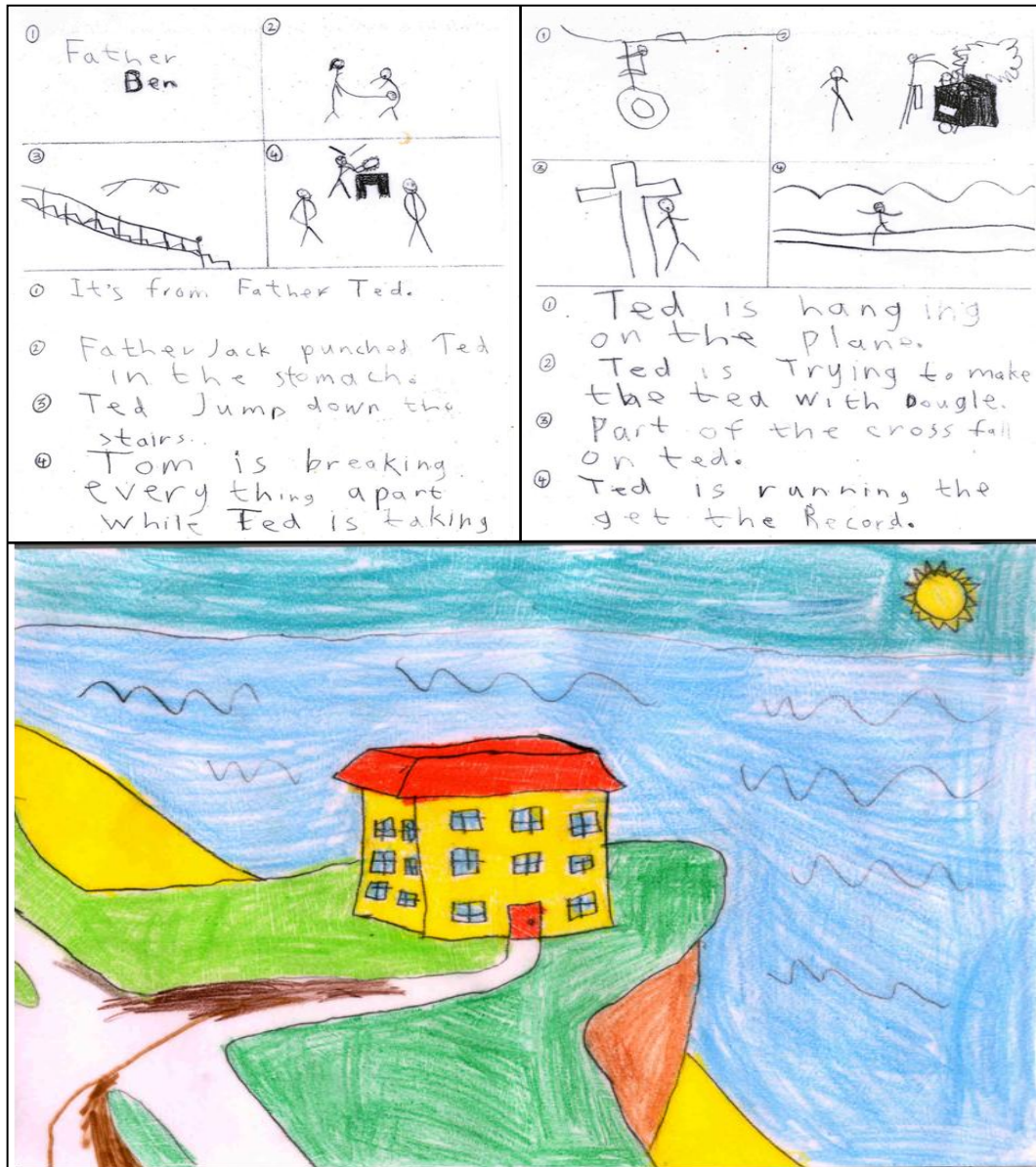
Establishing a shared narrative

Prior to the fieldwork I introduced Sean to 2 new DVD box sets; ‘Fawlty Towers’ and ‘Father Ted’, the latter of which he responded to with insatiable enthusiasm. My rationale for doing this was that since Sean needs narratives to establish communication, and since I had no idea as to what actually took place in his video games, if I could interest him in a narrative that I could actually relate to and understand, then we may at least share some common ground to allow us to generate conversation. Figures U & V are two ‘Father Ted’ story boards from episodes of ‘Father Ted’ that Sean finds particularly hilarious, while figure W is a drawing of Fr. Ted’s parochial house which, in contrast to his drawings from the ‘Aron narratives’ is particularly colourful and cheerful.

³¹ As I noted on day 12, “*for a person who is so consumed by computer games, he is willing to depart from them when somebody expresses a genuine interest in sharing a DVD with him. His desire for this shared [narrative] experience can overcome his desire to be alone in the world of computer games*” (Field notes- day 12- 23/06/2010).

³² ‘Turn taking’ (I’ll answer your question if you answer mine’) is a quite simple technique but I have found it to be (and still find it to be) extremely effective in maintaining conversation with Sean.

Figures U, V & W- 'Father Ted'



The 'double edge' of narrative processing- literal interpretation and personal complicity

In our pre-fieldwork interviews with Sean, in response to Loretta O'Sullivan's (Special Needs Assistant) question, "Tell me Sean, what are you pretending at the moment", Sean replied, "Alex Raven, a name I just made up. He's a male. He's a good guy. He was a taxi driver until New York was invaded by monsters, insect-like monsters, big green trolls. It's a pretty big invasion. Alex escaped with his family on a plane." [Sean used his thumb and forefinger to show the plane leaving] "His wife's name is Maria, his daughter's name is Emily, and his son's name is...." [Sean became upset and would not mention the son's name]

“The aliens came from another world called dragon world, most of the population of New York got killed. Listen Loretta, I feel guilty, so, so guilty that I made those people die” (Pre-fieldwork interview- 14/04/2010). This interview was, in retrospect, very significant as Sean revealed, for the first time, that he sometimes feels directly responsible for what transpires in the course of imagining out narratives (i.e.) he is not simply somebody imagining narratives out but *by* imagining them out he may feel as though he is directly (personally) complicit in how they play themselves out.

The ‘existence’ of fictional characters and their application to real life

On day 25 of our fieldwork, as Joe, Sean and I drove through the narrow, winding roads towards Gungan Barra on course for our pre-Carrauntoohil training hike, after a minor intrim period of echolalia, Sean apologised, *“Sorry, I wasn’t paying attention”* (to the historic landmarks that Joe was pointing out to him), and then unexpectedly brought his conversation with Joe to a deeply more meaningful level than it was previously. First, he said that he was sorry for not giving his brothers a turn on his video game the previous night, stating with distress, *“Joe, I’m addicted to video games!”* Then, suddenly, he brought up the death of his aunt Liz who had passed away from cancer in September 2009. Sean told Joe that *he knew that Liz might die* but people had told him that she wouldn’t die. And then she died. Sean went on to ask, in a very emotionally charged fashion, *“Joe, does heaven have saints?”* Then came the extraordinary part. Sean, in the midst of this emotional disclosure, very naturally referenced ‘St. Kevin’- a fictional character- from an episode of ‘Father Ted’ (Field notes- day 25- 22/07/2010). *“It was moving”*, I recorded in my field notes, *“to observe how Sean would reference St. Kevin from ‘Father Ted’ in relation to such a deeply tragic real-life situation”*. *“This again”*, I noted, *“speaks volumes of the importance that Sean lends to significant narratives and the literalness within which he interprets them”* (Field notes- day 25- 22/07/2010).

The infiniteness of narrative and the search for positive endpoints

In relation to narratives that do not have explicit literal endings Sean will invariably ask *“what happens to [the character] next”*, and will then suggests possibilities; *“maybe [he or she] will.... [future of character]... right?”* He even does this in relation to narratives that, for all intents and purposes, have actually reached an apparently logical endpoint. Writing up my

field notes on the evening of day 9, I reflected that “*Sean seems confused that there is no ‘next’ [upon the termination of a narrative], as if the narrative, like real life, continues on and on*” (Field notes- day 9- 18/06/2010).

Invariably, Sean needs the transient narratives that he is watching and processing (like the lengthy ‘Aron narratives’) to reach an endpoint; a conclusion, before he moves onto a new one (Field notes- day 3- 10/06/2010). This could well explain why in the aforementioned pre-fieldwork interview (14/04/2010), in response to Loretta’s question, “*Sean, do I upset you when I interrupt your pretend*”, Sean replied “*the more you try to tell me wake up the worse my pretending gets. It’s like when you have a nightmare and you’re interrupted, the nightmare just gets worse*” (Pre-fieldwork interview- 14/04/2010). Yet, pretending, for Sean, is not always a frightening process. It depends upon *what* he is pretending, and that depends entirely upon the types of narrative that he has been exposed to. Crucially, as Sean’s father mentioned to me at a recent planning meeting (18/06/2011), not only do narratives need to reach an endpoint for Sean but they need to reach a *happy* endpoint. This, in retrospect, may explain why Sean responded as negatively as he did during our trip to the ‘Titanic Heritage Museum’ in Cobh on day 11 (22/06/2010). As Sean’s father explained to me, 5 years ago, Sean became extremely upset having watched the popular ‘Titanic’ movie due to the fact that the hero, ‘Jack’ died at the end. This, John explained, had a devastating effect upon Sean who, from that point on, never again wanted to be reminded of the story of the ‘Titanic’ (Planning meeting- 22/06/2011).

The surface accessibility and aesthetics of child-orientated narratives

The narratives that Sean chooses to investigate, I contend, must have a *surface emotional appeal* in the first instance for him to become interested in them. These tend to be narratives that are not entirely dependent upon spoken language to be understood. They must be either funny (in a slapstick way), melancholy (having relationships which evoke strong emotions) or musical (having a musical soundtrack which helps to carry the narrative). It is only when a narrative appeals to Sean *on a surface aesthetic and/or emotional level* that, after a number of viewings, he will begin a deeper inquiry into it (Field notes- day 3- 10/06/2010).

For instance, the movie ‘When in Rome’ on day 13, was on one (childlike) level ideally pitched for Sean. There was an upbeat soundtrack which he enjoyed clapping along to. There

was comedy and there was a sense of romance that he responded to warmly by asking many questions about the woman and the numerous men that all fell in love with her through a magical spell. It appeared that the surface level of the narrative; the momentum generated by the music, the emotion and the humour, drew Sean into the narrative and, once he was drawn in, he began to deconstruct and analyse the relationships between its featured characters (Field notes- day 13- 01/07/2010).

The comprehension of complex adult-orientated narratives

Yet, it is not only childlike narratives that appeal to Sean. On day 9, Sean highly impressed me with his ability to attend to, absorb, and discuss what was a very complex and silent narrative. The '2 Dimensional Life of Her' (a live acting performance) in the Granary Theatre was described, in the theatre's programme brochure, as "*a performance work made of drawing, animation, puppetry, projection and paper that tells the story of an artist whose reality is infringed upon by an imaginary world that manages to escape from the confines of its two-dimensional existence*" (Field notes- day 9- 18/06/2010). Such was the obscurity and complexity of the narrative that I myself gave up on trying to follow it not 5 minutes into the performance. After the performance I had absolutely no idea whatsoever as to what had actually taken place in the narrative, never mind extracting some 'significance' from it as Sean did. This suggested to me that he has an uncanny ability to follow and comprehend extremely complex narratives which vastly surpasses my own ability in this area (Field notes- day 9- 18/06/2010).

'Pretending' - its mechanics, complexity and association with imagination and creativity

When I first met Sean in June 2008, it appeared that his system of pretending was something vastly more complex than traditional stereotypy's, tics or stims that we associate with autism. The sheer complexity of his hand and finger movements alone suggested some sort of language, not unlike sign language. Over the course of my first 2 years working with Sean I had managed to understand some of the meanings of his digit movements - his finger alignments; movements and sequences that, for instance, represent characters, characters talking to each other, characters in shock/surprise, vehicles and locations. Sean has shown me that when he is pretending he uses different finger and thumb symbols for 'characters' (thumb and index finger straightly aligned and tapped together to form a 'puppet talk'

action), ‘vehicles’ (thumb and index finger straightly aligned and moved in a straight line through the air like an aeroplane), and ‘locations’ (thumb and index finger forming a circle while touching at their tips).

I had a pretty good idea, by the end of our second school year, just before the commencement of our fieldwork, that this pretending came from the rewinding of narratives in his head that came predominantly from DVDs, comics and video games. Yet I had incorrectly assumed that while he was pretending, he was ‘locked into’- mechanically replaying- one narrative (i.e.) 1 DVD, or 1 video game, at a time. By the end of the first week of our fieldwork I realised that I had been utterly mistaken in this regard. In my field notes for day 6, I noted that *“what I have learned from talking to Sean, and observing his hand & finger movements, as well as his drawings, is that he does not simply ‘rewind’ narratives that he has seen in his mind, rather he mentally mixes, juxtaposes and intermingles multiple narratives and their multiple characters to mentally create and experiment with new character interactions and situations. Sean is able to hold multiple narratives in his mind at any given time (at least 3). To do this must be an extremely complex process requiring a great deal of both mental focus and mental flexibility. Imagine how difficult it would be for any person, were they asked to name 3 films they had seen in the distant past, or even recently, to simultaneously play all three films through in their minds, and then merge these narratives to create new semi-original hybrid narratives”* (Field notes- day 6- 15/06/2010).³³

It was on day 3 of our fieldwork when Sean’s simultaneous processing (‘pretending’ out) of the ‘Simpsons’ and ‘Father Ted’ narratives had first suggested to me that Sean does not become locked into pretending out one narrative at a time and that he *merges* narratives,

³³ It is difficult to know the extent to which these narratives are played one after the other versus the extent to which the narratives are merged. Either one of two things are happening and to identify which one would require a follow up study when the time would be right for Sean. When he is pretending he is either, a) imagining narratives sequentially, and intermittently ‘maximising and minimising’ them as one would do for instance when viewing multiple computer files, and then placing locations and characters from one into another in a follow up narrative- a difficult enough cognitive process in itself, or b) imagining narratives simultaneously. This is more difficult to explain as it would require him to have the facility to re-imagine more than one narrative at the same time. This, it could be argued would be impossible as it would require more than one memory module. This would be a perfectly reasonable rebuff of the hypotheses. However, it may well be that Sean’s deep and ongoing mental dissection and resection of narratives has been facilitated by a sort of ‘multitrack’ memory in relation to narratives which allows him to mentally play out a scene from the ‘Simpsons’ while playing out a scene from ‘Father Ted’ at the same time, thus facilitating instant interchange between the narratives. Imagine watching two different films on a computer screen, one on the left and one on the right, intermittently glancing at each one in order to keep track of them, and then having a technological facility whereby you could cut and paste characters, vehicles, and locations from one to the other.

plays with them and *experiments* with them in his mind.³⁴ Figure X shows Homer Simpson transported into an episode of Fr. Ted, in which he takes Fr. Dougal's place on the milk float.

Figure X- Homer on Dougal's milk float



On day 15, Sean's pretending out of multiple narratives included a string of famous characters who have made appearances in the 'Simpsons' (such as George Bush and Tony Blair), at least 2 different episodes from 'Father Ted', as well as scenes from the movie 'Click' (Field notes- day 15- 05/07/2010).

Essentially, I believe that Sean can take pieces of multiple narratives (including landscapes and characters) to construct *entirely new narratives from scratch* (although he insists that they are 'stolen') within which he can place *invented* characters, such as 'Aron' and 'Alex Raven', who have an emotional/moralistic significance for him (Aron, for instance, being a projected manifestation of Jesus representing 'good' and Alex being another hero trying to protect his family).

³⁴ On day 6, for instance, he placed a location from 'Father Ted' (China Town) within a location from the 'Simpsons' (Springfield); "*there can be a Chinatown in Springfield, right*" (Field notes- day 6- 15/06/2010). Later on day 6, Sean's 'pretending' on the journey to the swimming pool included at least 3 narratives being played out simultaneously in his mind- ('Father Ted', 'Hitch' & 'Mass Effect') (Field notes- day 6- 15/06/2010). It is interesting to additionally note that the 3 narratives that he was imagining out on this occasion were of 3 different *forms*; 'Father Ted' is a television series, 'Mass Effect' is a video game and 'Hitch' is a film.

Focus on a single narrative during its internalisation

While Sean mixes and plays with multiple narratives after he has seen them, *while* he is absorbing a new narrative he is, I am confident, completely focused upon the singular narrative that he is experiencing at the time and *is not simultaneously imagining out other narratives*. The ‘pretending’ which he does when he is absorbing a new narrative (as observed by watching his finger & thumb movements and listening to the dialogue he whispers under his breath) suggests to me that he attends with *full focused attention* to that specific narrative for its entire duration, without distraction from external stimuli or internal narratives/proactive inference (Field notes- day 3- 10/06/2010).

Narrative and the generation of externally expressible interests

I strongly believe that Sean’s personal engagement in narrative should be appreciated as a *skilfully creative internal process*. Yet, it should be noted in addition however, that the narratives that he creates and imagines can give rise to new *externally expressible social interests*. Sean’s ‘imagining’ is not simply an internal, isolated psychological process unto itself but can have, potentially at least, an *external social application* (Field notes- day 3- 10/06/2010). For instance, Sean’s interest in the ‘Chinatown’ episode of ‘Father Ted’ prompted an interest in Chinese people generally, evidenced by his impromptu approach towards a member of ‘McDonald’s’ floor staff on day 23 asking, “*Excuse me Mam, are you from China?*”

‘Pretending’, self-esteem, and communication

In our pre-fieldwork interviews with Sean he revealed to Loretta; “*I hate chatting Loretta but I’m fine. My mind is broken Loretta. It’s when your mind gets out of control, my mind gets out of control in class*” (Interview, 14/04/2010). One of the major challenges that Sean’s teachers and SNAs have had with Sean within the school context, from his ABA-based education until he reached the age of 12, to his current placement in my programme, is that of keeping him focused during lessons and to (as we have all been guilty of- including myself) getting him to ‘stop pretending’.

This has been an ongoing battle and one that has clearly not contributed anything positive towards Sean's self-esteem, deducing, as he did on April 14th 2010, that his mind simply must be 'broken'. Sean's mind is not broken. It just works differently (and in a far more complex way) than ours. The simple fact is that when Sean is 'bored' he genuinely finds it almost impossible to 'stop pretending'. It was for this reason that it was so refreshing to work with Sean outside of the school context, to be able to give him my full undivided attention, in a number of new contexts in which he wasn't constantly being told to 'stop pretending'. The change of context- from school to real life- allowed me to learn how to really communicate with Sean- on his terms.

In my field notes for day 16, I joyously recorded that *"today Sean was pretending out multiple narratives ('Click', 'Father Ted' & a video game) but, as was increasingly happening, he was dipping in and out of conversation with me more and more whilst he was pretending, often asking questions in relation to what he was pretending, such as if he could make the Garden of Eden into a planet"* (Field notes- day 16- 06/07/2010). As I had noted, on day 6, *"pretending and listening can [indeed] happen at the same time"* (Field notes- day 6- 15/06/2010). It was astonishing for me to discover how fluent conversation with Sean can become when he knows that he is not being judged, and his pretence, as far as the other is concerned, is nothing to be ashamed of. *"A conversation about what Sean is imagining at a given time, responding to questions and making positive comments is"*, I noted on day 16, *"as worthwhile as any conversation [that one can have with him]. [Such conversations] relate to what is important to him at a given time. This is the direct communication of his interests- narratives that have significance for him"* (Field notes- day 16- 06/07/2010).

Musical narrative and the development of non-visual pretence

The first song that Sean ever chose to listen to (and liked to listen to again and again) was the 'Westlife' track 'What about now.' This came about quite spontaneously in school in December 2009 when Sean came across a link to a 'Westlife' website when searching Wikipedia for some unrelated item of information. What so captivated Sean about this particular song still remains a mystery to me. I did not quiz him on this as I suspected that it was something deeply personal to him and that if I intruded I might alienate him. All I asked him was *"What do you like about that song?"* to which he replied *"I like to use it when I'm imagining."* This was, very interestingly to me, the first time when Sean was exploring an

entirely new form of narrative, one which was completely non-visual in nature. *Musical narrative* was bringing about a whole new form of pretending wherein Sean's fingers and thumbs, moving in fluid and graceful motions, appeared to be *dancing*. He was clearly replaying the song 'What about now' because either the lyrics, the melody, or both, touched an emotional nerve in him which brought him a sense of serenity (Field notes- day 13-01/07/2010).

Musical narrative and emotional engagement

Intrigued as I was by Sean's interest in the track 'What about Now', from the very first day of our fieldwork, I played 'Westlife' tracks for the duration of our car journeys together. I chose songs that were slow and emotional and repeated these songs every day. These songs were 'The Rose', 'All out of Love', 'The Dance', 'Desperado' and 'No more heros'. Sean did not appear to take too much interest in these new songs until day 13 when, suddenly, he expressed a keen interest in the song 'All out of love'. This was quickly followed, over the coming days, almost in domino effect fashion, by an interest in 'The Rose', and then 'The Dance' (all of which subsequently featured upon the soundtrack of 'Sean's Victory' DVD). As was the case with 'What about now', Sean continually replayed each new song as they appealed to him, almost as if (as is the case with people of interest to Sean which I will discuss later), *he was deeply investigating each one*. 'All out of love', for instance, featured a female guest vocalist (Delta Goodrum) whom Sean was enticed to find out everything about. What was most noteworthy, however, was Sean's expressed emotional reaction to each new song. His facial expressions, and his comments, such as "*it's so beautiful*" (referring to 'The Rose'), clearly suggested to me that music has the power to deeply move Sean on an emotional and indeed, I suggest, spiritual level. It was also heart warming that the process of listening to these 'Westlife' songs was one that Sean was willing to *share* with me, allowing for shared enjoyment in the process of listening to music together (Field notes- day 13-01/07/2010).

Musical narrative in a social context

It was precisely due to the fact that Sean's interest in 'Westlife' tracks was widening so rapidly, that I contacted national DJ (Michael Cahill- 2FM) who, through 'Westlife' front man, Nikki Byrne, acquired 3 long since sold out VIP tickets for the live 'Westlife' concert at

the Marquee, scheduled for Wednesday night, July 7th 2010. If this new form of narrative-musical narrative (if only encompassing ‘Westlife’ music at this point), I wondered, had the power to elicit such an emotional response from Sean, how would he respond to a live ‘Westlife’ show? Sean had never been to a concert before in his life and his parents feared that he may be unable to cope with neither the scale of the crowds, nor the noise levels. Would the scale of the crowds and/or the enormity of the experience overcome him? Or would he emotionally engage in the experience? This, at the time, was the question to be answered. But why?

Resonating in the back of my mind was the story of Greg, ‘The Last Hippie’ as described by Oliver Sacks (1995: 42-43)³⁵. “*Unable to recall events or encounters or facts into consciousness...unaware, indifferent, bland, placid, emptied of all feeling*”, Sacks explained how during an excursion to see what had been Greg’s favourite band, ‘The Grateful Dead’, “*Greg was transported by the excitement...the whole vast garden now in motion with the music, eighteen thousand people responding together, everyone transported, every nervous system synchronised, in unison*” (Sacks, 1995: 70). While Sean’s case is entirely different from that of Greg’s it was tantalisingly compelling to me to investigate how Sean would respond to more than just ‘Westlife’s’ songs themselves but to the *experience* of the ‘Westlife’ *performance*, the sheer scale of which may have been said to be too far outside of the comfort zone of a person with autism (Field notes- day 13- 01/07/2010).

‘Westlife’- Live at the Marquee, Wednesday night, July 7th 2010- Musical narrative and human connection

What was particularly noticable during the ‘Westlife’ concert on July 7th was how relaxed Sean remained throughout the entire course of the performance. His body language, his posture and his facial expressions captured on camera reveal a Sean completely unphased by neither the size of the crowd, nor the noise levels in the arena. Again, his hands and fingers, moving in slow graceful motions, appeared as though they were dancing (Field notes- day 17- 07/07/2010). But was Sean ‘*transported by the excitement...every nervous system synchronised in unison*’ as was the case with Greg at the ‘Grateful Dead’ concert? The

³⁵ Greg had become ‘gravely disabled, neurologically and mentally’ following damage caused by an enormous midline tumour extending on both sides into the frontal lobes, temporal lobes and forebrain (Sacks, 1995).

answer is, basically, no. There were some key differences between Greg's experience at the 'Grateful Dead' concert and Sean's experience at the 'Westlife' concert.

What seemed to fundamentally characterise Sean's experience at the 'Westlife' concert was not that of 'excitement', as was the case for Greg, but rather a deep relaxation, total and complete relaxed immersion into the experience in which he seemed to enter an entirely new state of consciousness. The connection (one that I feel privileged to have observed) was not between Sean and the other 5,000 fans in the arena, but rather between Sean and his mother Noreen. Thus to say that Sean was 'transformed' by experiencing the music he likes in a live context would be to miss the real significance of the experience of July 7th. It was the *sharing* of this experience with his mother that was responsible for the 'transformative effect' that I observed in Sean both during and following the concert. The video footage showed *two* nervous systems connected in unison, a most beautiful expression of love between mother and son (Field notes- day 17- 07/07/2010).

The formation of sustainable relationships

The process of investigation and formation of initial links.

In relation to every character that Sean comes across in the movies that interest him, and (during the period of fieldwork) the 'Father Ted' episodes, he will try to find out every possible item of information about those characters and will, in fact, become terribly frustrated when it is impossible to find answers to certain 'extractable' questions by virtue of the fact that the information he seeks simply does not exist within the narrative itself (Field notes- day 2- 09/06/ 2010). It is through *an intense process of investigation* into fictional characters that Sean attempts to implant these characters into his short-term memory. It is then by subsequently *linking* these characters to other characters that he attempts to retain them in his long-term memory.

Exactly the same technique applies to how Sean attempts to retain new *people* in memory. Sean does very easily tend to completely forget people whom he has previously met. However, the people who he *does* succeed in retaining in memory appear to be people who he has previously questioned in depth (particularly in relation to where they live, how old they are, what job they have, and what family they have); once he has extracted, essentially-

their *story*. Once he has this information at hand to contextualise the person in question he finds it easier, I suggest, to store them in his long-term memory. Then, provided that the person in question has responded to Sean's questions without judgement, by providing him with the information that he has requested, he will- if there is an available *link* to be made- connect that person to another person who has already made it into his long-term memory. This 'link' to which I refer is basically an *association* that can be made between people either in terms of *function* or *friendship*. Permit me to illustrate what I mean with reference to an incident which occurred after the period of fieldwork had come to an end.

In November 2010, a close family friend, Mr. Peter Deasy, came to work with me for a day in my office in school. Peter was there to help me with the editing of 'Sean's Victory' DVD. Before we commenced the editing process however, I brought Peter into the classroom next door to introduce him to Sean. As is typical of Sean, his first questions related to Peter's family, asking him "*do you have family*" and, specifically, if he had a mother and a father. When Peter explained to Sean that his father had died in a retirement home after being mistreated there, Sean- truly appalled- could only deduce that Peter's father had been murdered and was insistent that "*we have to catch that guy who murdered him!*" As the drama escalated, with Sean blatantly refusing to change the topic of conversation, and blankly refusing to accept my reasons as to why we couldn't just leave the school then and there to "*go get that murderer*", I eventually left the classroom with Peter, telling Sean that I would talk to him about Peter's situation later on that day.

Here is the critical part. Had this incident taken place prior to our fieldwork, I would have extracted no more significance from it than that it simply represented another example of Sean's inflexibility of thought, another illustration of a monumental 'theory of mind' deficit culminating in a highly disproportionate reaction to a simple story. Yet, having had the opportunity to learn about how Sean's social memory works, I realised that this incident provided me with a golden opportunity to extend Sean's 'web of personal linkages'.

Building a 'web of personal linkages'

This 'web' to which I refer consists of the people who, by linking them to one other, Sean has successfully retained in his long-term memory. At the time Peter visited us in school in November 2010, Sean's web of personal linkages of 'new' people (those outside of his

immediate family) consisted of Pat Falvey, Joe O’Leary, myself, the actor Cillian Murphy, and Cillian’s father, Brendan Murphy. But what had etched these people so concretely within Sean’s long-term memory?

Let’s begin with Pat Falvey and Joe O’Leary who led Sean to the summit of Carrauntoohil on day 29 of the fieldwork (28/07/2010). Not only had Sean deeply investigated Pat and Joe on numerous occasions over the preceding 2 years, but he had developed a trust and confidence in them over that period of time. During our journey to Cobh on day 11, for instance, Sean had intensely quizzed me in relation to my father’s immediate family. Sean wanted to know how Joe met my mother, how many brothers and sisters he had etc. As I elaborated upon Sean’s questions, relating to him the story of how my parents first met, as well as the occupations of my father’s many brothers and sisters, Sean displayed an intense interest in what I was saying, repeating back to me verbatim what I was saying as if he was learning it off (Field notes- day 11- 22/06/2010).³⁶ Then immediately upon meeting up with Joe exactly one month later, during our Gungan Barra training hike, Sean relayed back to him the story of how he had met my mother in extraordinary detail, to which Joe responded warmly and affectionately (Field notes- day 11- 25/07/2010).

Essentially, Sean never forgot Pat and Joe precisely because they always responded to his questions in a non-judgemental fashion, and never took offence at the many ‘inappropriate’ questions and statements that Sean, in all innocence, had put to them over the years, such as when meeting Pat for the first time and posing for a photograph with him in 2009 (after Pat had returned from training), Sean told him that he “*really outta take a shower*” (before departing for a scheduled meeting in Cork).

Having developed relationships with Pat and Joe, Sean then moved onto *associating and linking them in terms of friendship and function*. Pat Falvey, *the famous mountain climber*, Sean deduced, is friends with Steve’s dad Joe *because Joe is also a famous mountain climber* (No matter how many times I tell Sean that Joe is actually a teacher by profession, this is an item of information that he used to almost immediately forget). Thus, the Pat Falvey-Joe

³⁶ I am convinced, in relation to Sean, that echolalia can serve as a learning mechanism. As early as day 6, I recorded in my field notes that “*the conversation in the car (amongst countless other conversations) showed Sean using echolalia, I strongly suspect, as a way to maintain conversation, as well as a means of processing and retaining what is being said to him*” (Field notes- day 6- 15/06/2010).

O'Leary connection (with me hanging out there somewhere on the fringes) was the first link that Sean brought with him into the fieldwork exercise upon its commencement in June 2010- the first two links in the chain. Yet, as the fieldwork progressed, and I managed to switch my relationship with Sean away from that of teacher towards that of friend, I became much more powerfully factored into Sean's evolving web of personal linkages which by now had become a small, but very powerful, three-way chain.

Developing friendships- the atom analogy and 'the power of the web'

Imagine myself, Pat and Joe as 3 electrically-charged atoms. As separate entities, each atom, separately, and individually, has power. All three of us- Pat, Joe and I- as *individuals*, had established *individual* relationships with Sean. In the course of the fieldwork exercise however, (during which Sean spent much time with the 3 of us together, especially with Joe and I) those 'atoms' became, metaphorically speaking, *magnetically charged* and *connected to each other*. Thus, Sean was no longer dealing with 3 separate friendships which, being disconnected, are difficult to retain in memory, but now had the beginnings of a *connected web of friendship*.

Now imagine everybody else *outside* of Sean's existing 'web of personal linkages' as being *uncharged* electrical atoms, just randomly floating about in space, much like the disconnected items of information described in my discussion of 'weak central coherence' theory. Enter- Cillian Murphy and Brendan Murphy; the next two subsequent links in the chain. If one is to bring Cillian and Brendan into the 'atom analogy', one must ask, firstly, how did they become 'charged' in the first place and, secondly, how did they manage to 'maintain their charge' within the wider 'circuit' comprising Pat, Joe, myself, Cillian and Brendan, the extent to which, at the time of writing, whenever I meet Sean, the very first question that he always asks me is "*How's Cill?*"

The answer to the first question has its origins in nothing more than an ordinary, everyday experience; a random, unexpected occurrence which took place on day 13. As Sean and I exited the cinema theatre having watched the film 'When in Rome', I pointed Sean towards a poster advertising the movie 'Inception' which was hanging on display just outside the auditorium door, mentioning to him in passing that 'I had went to school' with one of the frontline cast of the summer blockbuster 'Inception', the Irish actor, Cillian Murphy, to which

Sean replied in exited astonishment; “*you mean you are the friend of a famous actor!*” (Field notes- day 13- 01/07/2010) Without thinking too much about it I went on to elaborate upon how Cillian and his family are connected with myself and my family. The following series of links thrilled Sean:

- Steve went to school with Cillian Murphy. They are friends.
- Cillian’s father Brendan is friends with Steve’s father Joe.
- Cillian’s mother Mary is friends with Joe also.
- Steve is friends with Brendan and Mary also. This is because Brendan is a teacher who Steve knows.
- Steve knows Mary because he used to work with her in his old school. This is also where Joe met Mary because Joe is also a teacher in the school that Steve used to work in.

(Field notes- day 13- 01/07/2010).

These associations were significant in terms of *the initial formulation of linkages*. But now to move onto the second, more important question; how exactly were Cillian, and his parents Brendan and Mary Murphy, *concretised* within Sean’s ‘web of personal linkages’? The answer to this question goes far beyond anything that the ‘atom analogy’ can do justice to. On one level it involved bringing Sean to see Cillian Murphy in the movies, such as when I brought him and his youngest brother, Ciaran, to see Cillian star in the movie ‘Inception’ on day 28.³⁷ That said, it was difficult to open up Sean to any of Cillian’s preceding films on the basis that most of them do not have happy endings. Similarly, Sean would not watch Cillian star in any film in which he plays the villain (which amounts to most of Cillian’s acting roles). Basically, he would not, and still will not, watch his friend, ‘Cill’, being a “*bad guy*.”

Thus, whilst acknowledging that it was not any broadening of interest in Cillian’s acting roles, nor in his acting credentials, that enticed Sean to so strongly internalise Cillian as a friend, how on earth- one may reasonably ask- did Sean, a traditionally very closed off, self-isolating young boy, come to develop such a fondness and affection for an actor whom he has never even met? The answer to this question is simple. It came from the manner in which

³⁷ In my field notes from day 28 I recorded that “*Sean absolutely loved the film ‘Inception’ because Cillian Murphy was starring in it and he was constantly speaking about the associations between Cillian, his mother and father, and myself and my father*” (Field notes- day 28- 27/07/2010).

Cillian's parents, Brendan and Mary Murphy, *treated* Sean when they met him on the occasion of his awards ceremony on the evening of December 14th 2010. Sean's 'internalisation of friendship' with Cillian came from his father Brendan's presentation of a beautifully framed, signed photograph of Cillian inscribed with an inspiring message from Cillian and his family. It further came from the inspiring words addressed directly to Sean from the platform of the stage by Brendan who said the following words;

“Cillian couldn't be here tonight Sean, unfortunately, but I've told him all about you, and I've told him all about your achievements and he's really, really impressed and he wants to send you his very best wishes. And he wants to say that he admires all that you have done and that he thinks you have achieved more in your own way than he has.”

Thus the *maintenance* and the *endurance* of Sean's 'web of personal linkages' is not something that can be explained mechanically. 'The power of the web', if you will, is that it is composed of people who are not only connected in terms of function, but who are connected in terms of a common history, wherein each person has individually demonstrated a genuine sense of care, interest and respect for Sean.³⁸

Recognising opportunities for new friendships and the 'widening of the web'

And this brings us back to November 2010, just one month prior to Sean's awards night, when Sean first met Mr. Peter Deasy. Leaving aside Sean's extreme reaction to Peter's story which limited the scope of their conversation on that occasion, it instantly struck me that Peter is somebody who could, very easily, be factored into Sean's existing 'web of personal linkages'. This was because, as Sean would read it:

- Peter is friends with Steve's father, and my friend, Joe.
- Peter is the man who cared for Joe's brother when he was suffering from Parkinson's Disease (a situation that Sean knew all about since our conversation during our journey to Cobh on day 11).
- Peter is also Steve's friend who helps him making DVDs.

³⁸ As I mentioned in my field notes for day 14, "*Sean mentions people like Pat Falvey, Joe O'Leary, Brendan Murphy, and Cillian Murphy as being his friends. Never has he applied the term 'friend' to any of his classmates either in the special class or in the mainstream setting*" (Field notes- day 14- 02/07/2010).

- Peter is a ‘knowledge’ guy. He is a ‘famous’ professor.
- Peter is also friends with my friends Brendan Murphy and Pat Falvey.

Basically, the linkage possibilities were very powerful. And on top of all that *we had a story*, to further contextualise Peter- the story of Peter’s father- one that I knew would stick in Sean’s humanitarian, narrative memory. And, sure enough, as Peter was setting up the video equipment to film Sean’s awards ceremony on the evening of December 14th 2010, Sean, noticing Peter at the back of the school assembly area, casually approached him, and almost as though he had known him for years, said, “*Oh hea Pete. I hope they got that guy who murdered your father.*”

Obstacles to the development of friendship- judgement versus acceptance

Yet, in order for Sean to develop friendships, success or failure in this regard entirely depends upon the communicative responses that he gets from others. And usually a positive response to Sean’s questions is something that is far from forthcoming. For instance, on day 4 when we met my mother in Cork city during our first shopping trip and Sean asked her, “*is there something wrong with your brain?*”, were it not that she *knew* Sean’s background I am certain that his question would have caused her a great deal of offence and prompted a response of alienation. This was one of countless incidents wherein Sean has asked ‘inappropriate’ questions, usually relating to a person’s physical features, ethnicity etc, which have very nearly landed him in a great deal of trouble on many occasions.

Questions, such as, “*what happened to your face?*” (directed towards a parent visiting the school- a woman in her mid forties with a type of acne), “*are you from China?*” (directed towards the aforementioned Pakistani woman working in ‘McDonalds’), and “*what kind of alcoholic are you exactly?*” (directed towards a college graduate who I took on for work experience who told Sean that he works part-time in a bar) all on the surface could appear as being intentionally rude and deliberately hurtful. One may be tempted to deduce (especially if one were to look back to the ‘Triad of Impairment’ for an explanation) that Sean, having autism, fundamentally lacks empathy and is pathologically indifferent to the feelings and emotions of others. The reality is, however, that nothing could be further from the truth (Field notes- day 4- 11/06/2010).

Sean's overriding personality traits, this study reveals, are his empathy for others, a consuming desire to help people who he feels need help, and an uncompromising belief in natural justice. But very few people around him actually understand this. When, for instance, it was observed during one of my school-based swimming outings (January 2010) that Sean would not interact with a visiting pupil, Padraig, who was joining us- a boy who was completely 'non-verbal' and grunted quite a bit, a number of people assumed that Sean was being deliberately rude. However, when I spoke to Sean about this later, it turned out that it was simply too upsetting for him to be around Padraig because he simply couldn't 'fix' Padraig's voice. Sean subsequently pleaded with me at length to find a doctor to "*fix his voice.*"

Similarly, Sean asked the woman with acne what was 'wrong with' her face because he genuinely wanted to know if it could be 'fixed'. He was similarly acutely concerned that Barry might be an alcoholic because in Sean's words "*You came from a bar!*" When he approached the Pakistani woman in 'McDonalds' he was simply trying to tell her that she was interesting to him because he became interested in Chinese people through watching 'Father Ted'. And, arguably the cruellest of questions cited above, directed towards my mother, was in fact intended as the kindest. Sean, who as it was revealed in our pre-fieldwork interviews is conscious that his 'mind is broken', simply wanted to make sure that my mother- Steve's mother, Joe's wife- didn't have to experience what he experiences every day. It was his way of saying 'I wish you well with your health' (Field notes- day 4- 11/06/2010).

'Reading' acceptance and rejection

On day 25, Sean was asking Joe copious amounts of varied questions throughout the duration of our journey to Gugan Barra including:

- "*Why did you shave off your gotie?*" (A beard Joe previously had)
- "*What's wrong with your hands?*" (Joe has white vitiligo patches on his hands)
- "*Did you brush your teeth?*" (Joe has quite blackened teeth)
- "*How many different types of car are there exactly?*"
- "*Where does rain come from exactly?*"
- "*What type of technology is it exactly?*" (Pointing to Joe's car stereo)

- “*Where did you meet Pat Falvey exactly?*”

(Field notes- day 25- 22/07/2010)

Again, the nature of some of these questions would probably be greeted with offence, and certainly with acute alienation, did Joe not *know* Sean. And while Sean does not realise when he may be causing ‘offence’, he certainly has the capacity to read when his presence is not welcomed. In other words, *he has the capacity to recognise and internalise rejection but he has absolutely no awareness of what might have caused it in the first place*. But because Joe *knows* Sean, and is genuinely fond of him, Joe knows that Sean means no offence and actually finds Sean’s directness and frankness to be a very endearing quality.

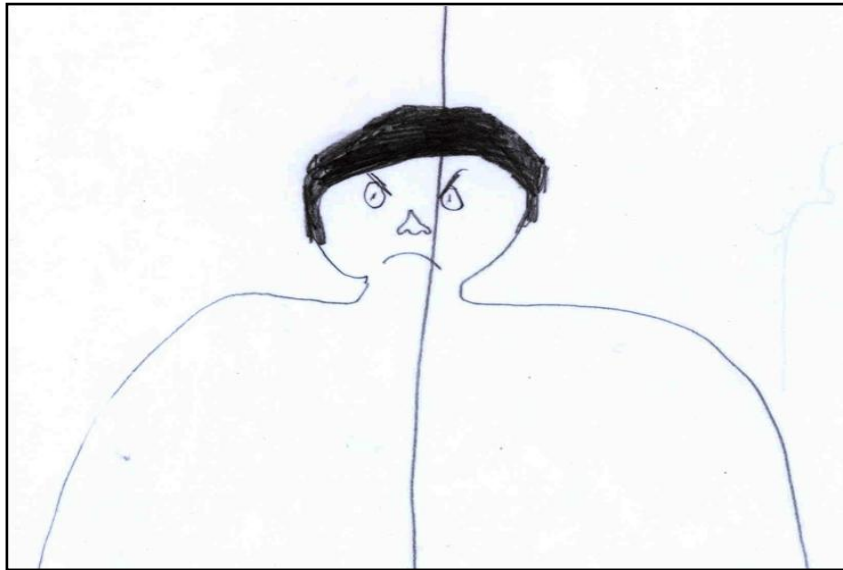
On day 25, Joe responded to all of Sean’s questions in a light hearted but adult fashion, and most crucially, he explained *exactly* what vitiligo is, the problem with his teeth, where rain comes from, how he met Pat Falvey *exactly* as well as the *exact* make and model of his car stereo. It was that sort of frank, non-judgemental, adult interaction which Joe extended to Sean that *Sean read*. Sean may not have the facility to read the ‘appropriateness’ of his own verbal communication towards others but he certainly has the facility to read the communicative response that he gets back from others which can be read from a number of cues (Field notes- day 25- 22/07/2010).

Personality and self-esteem

Commitment to the principle of ‘good’

Sean is committed entirely to the principle of ‘good’. One of Sean’s most telling drawings, figure Y, is that of Aron’s face with a line drawn down the middle. On the day he created this drawing for me, he pointed to the right hand side of Aron’s face and said “*I’m going to choose the good side*”.

Figure Y- Choosing a 'side' of Aron



The fact that Sean is so fastidiously committed to the principle of 'good' can only, in my view, be explained with reference to his innate *personality*. That is to say that underlying all of the surface features of autism lies a central person- *Sean*- a human being, whose nature and personality predisposes him to acting primarily in the best interests of others when given the opportunity (Field notes- day 1- 08/06/2010).

Empathy for others

On day 19, Sean's interactions with Mr. Hugh O'Leary³⁹, his golfing instructor, again revealed a young man with a keen sense of respect and empathy for the feelings of others. As we lagged behind Hugh and Joe on the golf course, in the pouring rain, Sean protested to me that he 'hates golf', yet he accepted that he shouldn't say this to Hugh as I told him that this would "*hurt Hugh's feelings*"⁴⁰ (Field notes- day 19- 09/07/2010). Yet nothing could prepare me for what happened later on that day.

³⁹ I did not request a follow up interview with Mr. O'Leary as his wife was heavily pregnant at the time and Mr. O'Leary needed to return to her immediately following our golfing outing.

⁴⁰ While Sean accepted this, later when Hugh told Sean that it's OK not to like golf, "*it's not for everyone*", Sean was quite irate with me that I had said that saying this to Hugh would "*hurt his feelings*" when clearly it didn't. He was right, I was wrong.

An unplanned visit to the home of my 97 year old grandmother, a visit suggested by Joe, revealed the true depths of Sean's compassion and empathy for others. Here Sean displayed all of the social skills, if not superior social skills, typical of any boy in his mid teens. He displayed enormous compassion and exquisite manners appropriate to meeting a very elderly lady, in a very similar way as to how he interacts with very young children. Sean was visibly moved by meeting a person coming towards the end of life's journey and the way in which he interacted with my Grandmother (particularly in terms of his body language and the gentle way in which he shook her hand) was very touching for me to witness personally.

Afterwards, my Grandmother commented upon what a "*beautiful young boy*" he is, how "*well dressed and well spoken*" he is and that how "*you would know that he comes from a good family*" (Field notes- day 19- 09/07/2010).

Self-concept and self-esteem

At the outset of our field work exercise, after over two full school years of working with Sean, I had absolutely no idea that his self-concept and his self-esteem were as low as they actually were. The first hint of this came during days 1 and 2 in relation to Sean's dislike of being filmed. The fact that Sean was so 'camera shy' at the beginning of the field work was far more significant than I had first realised (Field notes- day 2- 09/06/ 2010). And I subsequently realised that some of this may have been partially attributable to the nature of his relationship with his siblings.

On day 18, following my trip to the cinema with Sean and his 2 brothers, Conor and Ciaran, Ciaran's (Sean's youngest brother) bemused exclamation that I should not allow Sean to pretend in public (when Sean was using his hands and fingers to pretend while walking through the shopping centre) because, as Ciaran emotionally exclaimed, "*people will think he's crazy*" suggested a causal resonance with Sean's insistence on day 14, as he and his classmate John stood outside Trabolgon leisure complex, that I should not film him while pretending because, in his words, "*people will think I'm crazy*" (Field notes- day 18- 08/07/2010). In addition to the 'crazy' issue, there appeared to be an ongoing power struggle on the part of Sean's brothers for the attention of those around them and their brother.

Sibling rivalry

On day 22, having departed once again for ‘Trobolgon’ swimming pool, but on this occasion with Sean and his brothers, within the first 5 minutes of the car journey a major argument had broken out between them. It was clear that Sean’s brothers wanted my full attention, and being, as they were, slightly over-excited in the back seat of the car, Sean pleaded to his brothers for “*peace and quiet*”, to which his youngest brother responded in a less-than-amused fashion. Eventually I had to stop the car after a half an hour and split the boys up between my car and Sean’s brothers’ support worker’s car who was accompanying us to Trabolgon (Field notes- day 22- 14/07/2010).

In the swimming pool there were no arguments, although Ciaran demanded my undivided attention, while Sean withdrew alone to the shallow end of the pool, quite deflated by the whole experience, fixatedly and repetitively running water through his fingers (Field notes- day 22- 14/07/2010). A similar incident occurred on day 27 when Sean and I unexpectedly came across his brothers in ‘Leisureworld’ swimming pool when, after having observed Sean’s impromptu approach towards the lifeguard and swimming instructor, Joanne, on day 23, I had arranged a one-to-one swimming lesson between them. On this occasion, when Sean’s brothers approached us in the pool they started telling him how to swim, and spoke over his swimming instructor, Joanne. Unsurprisingly, Sean immediately wished to leave the pool. Yet the real tragedy was that while Sean’s brothers were both simply (in their own minds) innocently seeking the attention of Joanne and I (as all children do) by demonstrating how good at swimming they had become (Joanne had previously taught them both how to swim) they had *absolutely no realisation* of how their behaviour towards their brother caused him to wish to disengage and leave the pool which, ironically, they saw as being somewhat odd (Field notes- day 27- 26/07/2010).

Developing sibling relationships

On day 22, I reflected in my field notes that “*after 2 consecutive days of observing a highly relaxed, openly communicative, ‘transformed’ Sean (days 19 & 20) it is a source of immense disappointment to me to observe how on day 22 Sean could so rapidly ‘retransform’ back into his own self-isolating world due to the nature of his brothers’ interaction with him*” (Field notes- day 22- 14/07/2010). This, in retrospect, was an unfair observation. Sean’s

brothers genuinely wanted to help Sean but they simply didn't know how to do this without alienating him. As I further noted on day 22, it is essential to bear in mind that these are two *children* who, whilst being aware that their brother has autism, have absolutely no idea how autism actually affects their brother and the allowances and sensitivities they will need to develop in order to have a relationship with him (Field notes- day 22- 14/07/2010). This further confirmed what I had noted on day 18, namely the importance of developing an educational programme for both of Sean's brothers to help them to communicate with him more successfully (Field notes- day 18- 08/07/2010).⁴¹

Furthermore, it would be unfair, misleading and inaccurate to suggest that Sean's brothers were always the protagonists in every single conflict which arose between them and Sean. For instance, on day 28, following our cinema outing to see Cillian Murphy star in 'Inception', from *Ciaran's* perspective how hurtful it must have been that his older brother refused to mark this occasion by standing for a photo with him (Field notes- day 28- 27/07/2010). From Ciaran's perspective this type of behaviour may well have been why he had called Sean a 'mean brother' in the past. We need to view this from the perspective of a very young child (of only 9 years) with the best of intentions, but with *no understanding* as to *why* his older brother behaves in the way he does.

I feel absolutely certain that it will be possible to improve the relationships between Sean and his 2 brothers. Ultimately, these boys love each other. They have demonstrated that they can get along very well together when they are engaged in a shared activity that appeals to the three of them equally (Field notes- day 3- 10/06/2010). On day 3, for instance, this involved watching a funny DVD together. Sean's father, John, reported in our meeting (23/02/2011) that it is a similar case when the boys are playing video games together, which is why he and Noreen converted the large upstairs landing of their home into a large multimedia gaming area. The same scenario was true in relation to their interaction in the cinema on day 28. The 3 boys happily enjoyed the experience together. Finally, the hero's welcome that Sean's brothers extended to their brother upon his victorious return from Carrauntoohil on the night of day 29, vividly illustrated the depth of love which both Conor and Ciaran hold for their older brother. Both John and Noreen expressed how Sean's ascent of Carrauntoohil had a

⁴¹ Since the completion of the fieldwork I have piloted such a programme with Sean's brothers which, to date, appears to be very effective.

very significant impact upon Conor and Ciaran who, for the first time, saw their older brother achieve something truly heroic (Field notes- day 30- 29/07/2010).

The child-adult issue

The child in Sean

On day 9, as we entered the Granary theatre to see the ‘Two Dimensional Life of Her’, Sean’s first question to me was “*where are all the little kids?*” (Field notes- day 9- 18/06/2010). This was most likely due to the fact that this was the first adult-orientated live theatrical performance that Sean had ever attended in his life. But this is not to suggest that Sean dislikes younger children. In fact, he relates to children who are considerably younger than he is far better than he does to teenagers of his own age. Sean loves sharing in narrative experiences with younger children who enthusiastically and un-judgementally share his love for slapstick humour on a childlike level. This, for instance, had been clearly evident at a Christmas pantomime performance of ‘Snow White’ in Cork Opera House in December 2010. A further example of Sean’s affinity for children played itself out on day 14, as Sean stood in line for the water slide at ‘Trobolgon’. He had no difficulty, while waiting in line, in striking up a conversation with a little girl of approximately 7-8 years of age (Field notes- day 14- 02/07/2010). Meanwhile, on day 15, while Sean had no interest in the bowling *activity* with Loretta’s children, Abby (8 years) and Ross (5 years), he took advantage of the sound that his bowling shoes made, performing an extravagant tap dance routine upon the timber floor of the bowling alley, much to the delight of Abby and Ross (Field notes- day 15- 05/07/2010).

The adult in Sean

Yet while Sean can *relate* very well to young children *he does not see himself as a young child*. In fact, he has a complete aversion to anything that he considers to be for ‘little kids’. As John and Noreen explained to me, Sean will not enter their living room when his youngest brother, Ciaran, is watching childish cartoons. It was only at a real push, in fact, that Sean agreed to go to see ‘Shrek the Third’ with Ciaran on day 18 (08/07/2010). The only animated programme that Sean will now indulge in is ‘The Simpsons’ and, even at that, he will only

watch ‘Simpsons’ clips privately on the internet, in the hope that, as Sean’s father suspects, he will not “*get caught being a kid*” (Planning meeting- 20/07/2011).

The child versus the adult- performance outcomes

Ultimately, the point is not to deny the ‘child’ in Sean but also to acknowledge the adult in him (Field notes- day 9- 18/06/2010). And when one reviews the evidence- 31 days of field notes, interviews and video footage- it is glaringly obvious that Sean performs best when he is treated and respected as an adult. Conversely, when he is treated as a child, he withdraws completely back into himself. This was the case, for instance, on day 7 when Sean’s support worker⁴² took him crab fishing on a beach with a child’s net in the company of children who could not have been more than 6 or 7 years of age. Deflated, and I suspect embarrassed by the situation, Sean wandered alone along the beach and sat on the shoreline in self-imposed isolation, with his head down, repetitively running sand through his fingers, in classically autistic fashion, in much the same way as he did (with water) on day 22 in Trabolgon swimming pool (Field notes- day 7- 16/06/2010).

However, on day 1- in complete contrast- Sean’s highly directed conversation with a pharmacist in the village of Kinsale, in relation to the dangers of smoking, (I had popped in to pick up some ‘Nicorette’ chewing gum) was an exquisite example of how Sean can spontaneously enter into very intellectual, adult-orientated conversations with others when the subject matter is something that he believes in strongly, when he is respected as an adult, and when his opinion is both valued and responded to appropriately (Field notes- day 1- 08/06/2010). The adult in Sean always shone through, in all of its intensity, throughout the course of the fieldwork, when he was not treated as an autistic child, but rather as the principled and determined young man he is.

The development of key relationships

Day 15 marked a point in the fieldwork wherein I began to fundamentally question whether or not the project would really help Sean to open up communicatively to those around him. It

⁴² Sean’s support worker from a local service provider used to provide Sean with 1-1 support in the community for 2 hours per week.

was becoming clear to me that the degree to which Sean would now very naturally communicate with me may not necessarily ‘transfer’ or ‘generalise’ to all those around him, or in particular to peers of his own age. I was forced to realise that meaningful relationships with Sean can only be developed through consistency of experience and earned trust with a level of understanding that adults, rather than children, are best placed to offer him. “*Sean may perhaps never*”, I conceded on day 15, “*immediately ‘open up’ communicatively to a person who he meets for the first time, and he may well always use his ‘pretending’ as a defence mechanism when he is under pressure socially.*” “*However*”, I added, “*this does not mean that he may not develop a small number of meaningful relationships with people to whom he can relate on an adult level*” (Field notes- day 15- 05/07/2010). The conditions for the establishment and sustainability of such meaningful relationships became subsequently clearer following a closer analysis of how Sean internalises both acceptance and rejection, culminating in my investigation into his aforementioned ‘web of personal linkages.’

Before I proceed towards offering some more concrete, stated conclusions in relation to the dynamics of *choice, control, challenge* and *risk* which underpin the development of sustainable relationships between Sean and others, I would like to briefly consider the perceptions and responses (including my own) of some key fieldwork activity leaders towards Sean (with the exception of Pat Falvey- he will be addressed in a separate section) to investigate further how Sean responded to those perceptions and responses, and how specifically these impacted upon the *performance outcomes* of some key activities involving challenge and risk.

Control and opportunity

On day 8, in ‘Hop Island’ Equestrian centre, when questioned as to Sean’s level of progress in relation to horse riding, his instructor, Mr. Jason Carey replied: “*I think he finds it hard to focus and if he had the focus he’d have the ability no bother. But it is just trying to get him to focus. He’s got a lot of things rabbiting about in his head.....it’s just trying to hold his interest is the main part*” (Field notes- day 8- 17/06/2010). With all respect to Mr. Carey, (and he is an extremely kind and ingenuous man) Sean was never going to focus until he had a *reason* to focus. Sean was never going to focus until Mr. Carey left go of the rope connecting himself to the pony; until he granted Sean *control*. Unlike choice (which will be discussed later), *Sean does not fear control*. In fact, he craves it and responds to it with an insatiable

sense of enthusiasm. *Sean longs for control*. In addition, I would venture to argue that it is when Sean is denied control- when he is treated as a child, as opposed to an adult- that he retreats into his own world of autistic aloneness.

But, unfortunately, Sean was never granted control during this activity on day 8. During his horse riding exercise Sean completely engrossed himself in his world of pretence, shutting down entirely for the duration of the activity simply because, I suggest, he had no real control over the pony that *he* was apparently supposed to be riding.⁴³ And this was all in spite of the fact that Sean had attended horse riding lessons for a number of months previously under the supervision of Mr. Carey, an activity arranged by his local service provider support worker. And while I have absolutely no expertise in assessing the safety risk pertaining to permitting of a person to ride a horse unaided, I would seriously question the rationale behind the repetition of a recreational activity which one will never, realistically, be allowed to perform even semi-independently.

Nonetheless, I maintain that if Sean can drive a yacht, Sean can ride a horse. It is really, in my view, just a matter of granting him *opportunity*. On day 5, when Sean was granted control, he was perfectly able to drive an extremely powerful yacht through Crosshaven harbour. On this occasion, Mr. Brendan Cronin's (Sean's instructor's) approach was entirely different from that of Mr. Carey's. Throughout the course of their interaction with Sean, both Mr. and Mrs. Cronin (his wife who accompanied us) never once approached Sean as being an autistic individual. And this was obvious from their very first handshake with him on the marina. "*Once you introduced him to me*", Mr. Cronin reflected in our interview, "*I knew straight away he was into conversation*" (Interview- day 5- 14/06/2010). (If only Mr. Cronin knew that the hour-long conversation he subsequently had with Sean aboard his yacht was such a rare accomplishment) Essentially, Mr. and Mrs. Cronin treated Sean as a unique *person* with ambition, capability and intelligence; not as an autistic child with all of the pre-judgemental baggage that such a label carries with it. And, as a result, that's exactly what they got.

⁴³ As the instructor, Mr. Carey, had full control (never leaving go of the rope) Sean seemed to be almost unaware of even being on top of the pony. Thus he spent the entire duration of the activity pretending in relation to 'Father Ted' while simultaneously fixatedly plaiting the pony's hair, becoming suddenly upset when he accidentally pulled too strongly upon her mane causing her a brief moment of distress (Field notes- day 8- 17/06/2010).

Control and regulation of time

The yachting (day 5) and go-karting (day 16) activities (which will be described in detail later) were examples of times when Sean no longer needed to know ‘how long is left’, became vividly aware of his surroundings, and generated & responded communicatively with others in a way that made him, for a time, appear to me as being completely ‘unautistic’. Essentially, Sean’s constant insistence on knowing ‘how long is left’ ceases to become an issue when Sean is in *control* of the activities in which he is involved. This is because, in my view, he is *invited to focus*. To briefly return to day 5, what the yachting activity showed me, as the karting activity subsequently confirmed, was Sean’s ability not only to stay focused when granted control, but to *stay globally focused on a number of things simultaneously*. While in control of the yacht Sean completed a number of tasks at the same time. Firstly, he steered the craft for an extended period of time. He was able to keep the craft on course by ‘feeling’ and responding to the ocean currents. This, Mr. Cronin informed me, is an extremely difficult thing for a novice sailor to manage. I myself found it very difficult to do but Sean seemed to be able to do it naturally. Secondly, he simultaneously maintained an ongoing conversation with his captain, Mr. Brendan Cronin. He *generated conversation* by asking Brendan multiple questions about the instruments and controls on the vessel (‘Father Ted’ never once featured in conversation) and *responded with perfection* to all of Mr. Cronin’s instructions. Thirdly, he *simultaneously* monitored where the craft was in relation to the coast and to other vessels, as well as the intended direction of the craft. Ultimately, he demonstrated *global, flexible attention; a full awareness of his surroundings in their entirety*, and a keen sense of observation (Field notes- day 5- 14/06/2010).

My yachting experience with Sean on day 5, as well as my karting experience with him on day 16, forced me to redirect my thinking completely, away from my long held false assumption that ‘Sean can never be given control over activities that involve risk *because* he pretends’, towards the more accurate realisation that ‘Sean pretends *because* he is not allowed to take control over activities that involve risk’ (Field notes- day 5- 14/06/2010). These activities showed how (after years of failed attempts) Sean’s ‘pretending’ could be controlled to the degree that he could strike a balance between ‘pretending’ and ‘paying attention’. The answer to this question, as it turned out, was a surprisingly simple one; just give him more say in, responsibility for- and control over- his own actions (Field notes- day 5- 14/06/2010).

Control and global attention

On the morning of day 16, before we left Sean's family home to depart for the go-karting track in Watergrasshill, Sean directed a question towards myself and his father John that, in retrospect, was one of the most poignant questions that he asked throughout the course of the fieldwork. It was, simply; "*Will I be free?*" By this Sean was asking us if he would be allowed to drive a kart on his own (Field notes- day 16- 06/07/2010). When we arrived to the race track however, the receptionist insisted that Sean would have to go in a double 'dual control' kart with me after I had foolishly told her that Sean has autism. Though disappointed, I accepted this, particularly when I realized that "*it was a very wet, slippery, serious looking track with pretty powerful karts*" (Field notes- day 16- 06/07/2010).

When I got into the dual control kart with Sean I took full control over the power. Sean was barely even assisting with the steering, appearing, as was the case when he was on the pony 8 days previously, barely even present. Yet my instant feeling, as we slowly circled the track, was that there was no way he could drive this machine on his own. The steering was heavy and a driver had already gone off. That said, I wanted to get some video footage so I asked an on-site instructor, 19 year old Mr. Gavin Daly, to drive the kart with Sean while I shot some film and photographs. I asked Mr. Daly to make an assessment as to whether Sean could possibly be left off on his own, but I was certain that the answer would be no. Amazingly though, after only two practice laps, Gavin and Sean pulled into the pits whereupon Mr. Daly assured me that Sean "*would be well able- definitely*" to drive a single-seater kart unaided. Nervously, having accepted Gavin's assessment and recommendation, I apprehensively watched as Sean pulled out onto the racetrack alone in a single-seater kart.

The first thing I noticed that simply *stunned me*, was how proficiently, before pulling out of the pits, Sean took a fleeting glance over his right hand shoulder in order to check for oncoming traffic with a sense of naturalness that made him appear as though he had been driving for years. And Sean had never before in his life driven a motorised vehicle. Sean's approach in racing his kart was to do 2 to 3 laps, and then come back into the pits for a rest stop. Yet he kept wanting to go back out. Cold and saturated in rain, he kept wanting more. With each series of laps and pit stops, his confidence and speed increased.

This was only the second time (yachting being the first) that I had ever witnessed Sean engage in an activity wherein he didn't constantly keep asking me 'how long is left'. He was, in fact, disappointed when I told him that he had only 5 minutes left on the track. The video footage captured shows how, with each lap, Sean's confidence grew and grew, as he again applied *sustained global attention* to the task at hand. The freedom was something that he clearly relished and this freedom certainly had a profound effect upon his confidence and performance. Later that evening when I complemented Sean upon his acute sense of driving observation and skill, he humbly replied that it was "*just something I learned in a video game*" (Field notes- day 16- 06/07/2010).

Mr. Gavin Daly's comments, in his description of his experience of people with autism; "*I've had not a problem with any of them at all like, they're all actually perfect like, not a problem at all, they're better than most normal kids who come up here, they're actually perfect like*" (Interview- day 16- 06/07/2010), further suggested to me that, as Clough (1995) maintains, *research does indeed create its objects*. Like Mr. and Mrs. Cronin, due to his approach towards and interaction with Sean, Mr. Daly got exactly what he expected to get out of him.

Respect, understanding and the nature of knowledge

On day 26, Sean had his first martial arts session with Mr. Corin Morgan Armstrong, a world class Tae Kwon Do Instructor from Bridgend, Wales, who also- incidentally- has a vast knowledge of world history. Having told Sean about this on our way to collect Corin, he instantly began quizzing Corin, throughout our journey to the studio, upon a series of complex historical questions which subsequently evolved into a highly intellectual conversation lasting for over 25 minutes (Field notes- day 26- 23/07/2010). Although Sean was not motivated by the Tae Kwon Do activity itself (albeit Corin in our subsequent interview saw some motivation there), he was extremely interested in Corin himself and the knowledge that he not only had at his disposal, but was willing to share with Sean. It was as though, because of this, Sean did not want shift his attention away from Corin himself, who Sean, far from relating him to the activity of Tae Kwon Do, later referred to as the "*knowledge guy*" (Field notes- day 26- 23/07/2010).

Mr. Morgan Armstrong's reflections upon meeting Sean (Interview- 26/06/2010) suggested to me further *that how one view's/judges another person will inevitably have an impact on*

the communicative interaction that plays itself out. Mr. Morgan Armstrong reflected in our interview that Sean had “*clearly gone out of his way to find out about these things that interest him and he has retained that knowledge and he can reflect that knowledge back to you in a conversation in quite an adult way I thought for his age you know regardless of the fact that he is autistic*” (Interview- 26/06/2010). Crucially, Corin responded to Sean’s questions enthusiastically and in a very adult fashion. In other words, his in-depth piece of sustained discourse with Sean was made possible through his *responses to Sean on an adult level* which communicated to Sean a genuinely adult respect for his interests. Corin’s entire approach towards Sean- both in conversation and during their Tae Kwon Do session- was that of a person who was completely unphased by the fact that Sean has autism. He was primarily interested in *the person* Sean and not ‘Sean who has autism’ (Field notes- day 26- 23/07/2010).

Yet while Mr. Morgan Armstrong clearly made no prejudgements about Sean in relation to his autism, it would be dismissive to suggest that he completely disregarded the fact that Sean has autism. In fact, he demonstrated an implicit awareness and knowledge surrounding the nature of autism and how it can affect an individual, which was born out of his experience in training children, adolescents and adults with autism in his own club in Bridgend (Field notes- day 26- 23/07/2010). “*I’ve taught a couple of autistic children over the years*”, Mr. Morgan-Armstrong explained to me, “*over the last couple of years I’ve trained with and taught with a guy who, he’s twenty one....has quite severe autism....He’s a huge guy, a massive physical bloke, and quite brewing and quiet but once he feels comfortable and confident with someone he’s happy to approach them and talk to them*” (Interview- 26/06/2010).

What is, I feel, important to acknowledge here is not only the importance of having *knowledge* (in this case Corin’s knowledge about autism) but *to what purpose that knowledge is put*. ‘Knowledge’, ‘*my knowledge of you*’, I argue, can be interpreted in any way and used for any purpose. What is important to consider, in my view, is that the ‘ideological baggage’ which one may attach to that knowledge is precisely what makes the difference between whether that knowledge is used for either constructive or destructive purposes. Mr. Morgan Armstrong *could have* interpreted what he knows about autism as constituting an immovable barrier to participation in a sport which he himself, a 5th Dan instructor, competes in at an international, world-class level (Field notes- day 26- 23/07/2010). Yet far from adopting an

elitist approach, Corin demonstrated an implicit awareness of how his sport can be a vehicle for the self-empowerment of individuals, not only people with autism, but, as Corin explained “*all kinds of kids...kids with criminal records, kids who are in trouble with the police, kids who are dabbling in drugs, kids who are like violent at school, autistic kids, kids with Aspergers, you know all sorts of different problems*” (Interview- 26/06/2010).

Challenging my own assumptions

On day 31 (30/07/2010), in my interview with Sean’s parents, there appeared to be an almost unspoken sense of guilt expressed by John and Noreen that they had been ‘setting the bar too low’ for Sean in the past because, they had felt that many of the feats that Sean ultimately achieved in the course of our fieldwork would have been beyond him. However, there was one hugely significant admission that I failed to reveal to John and Noreen during that interview. This was that *I myself, initially, in the back of my mind, always half doubted Sean*. I never spoke of these doubts but, for instance, I genuinely believed that it was utter lunacy for my uncle Brendan to put Sean in control of his half-million euro power boat. I was fully convinced that Sean would crash the kart on the race track, and none of us ever believed that he would make it even half of the way up Carrauntoohil.

And yet *every single time* Sean proved us all wrong. “*Carrying out this type of field work*”, I reflected in my field notes for day 31, “*really requires depending more upon blind hope and faith than it does upon trusting in your own anxieties and preconceptions. And this is a very difficult thing to do, especially when, with the best of intentions, you want to do nothing more than to primarily protect the person*” (Field notes- day 31- 30/07/2010).

I did not create all of the opportunities that Sean availed of over the course of our fieldwork. It was those open-minded people with whom he came into contact who created all of the opportunities. In all honesty I had no idea that Sean would actually be given the opportunity to do drive Mr. Cronin’s yacht- it was Brendan alone who took the initiative in sharing control with Sean. I honestly did not believe that Sean would have had either the strength nor the skill to independently control the craft. The idea of ‘sharing control’, in a real way, had not been a seriously, pointed consideration of mine until I witnessed the transformation in Sean played out before my eyes as I filmed him over the course of the hour long activity in Brendan’s yacht on day 5. One further admission; on the issue of driving on day 16, despite

my rhetorical disappointment in relation to the karting company's policy to disallow children with autism to drive the karts alone, I was- in all honesty- secretly relieved. It gave me a potential way out to avoid risk. In this instance it was Mr. Gavin Daly who challenged me to challenge my own assumptions and to give Sean an opportunity to prove his driving ability.

Similar underestimations of Sean, on my part, were true in relation to much more minor activities- underestimations which, in retrospect, were utterly unwarranted. Yet, *at the time*, these fears seemed very real because, again, my primary priority was to *protect* Sean. For instance, on day 14, at 'Trobolgon' swimming pool, when I asked Sean if he would like to go down the 15 meter water slide, I suspected that like John (his classmate who accompanied us), he would be too afraid to but I figured that perhaps he might give it a try if I went up the very steep 15 meter ladder with him. As Sean didn't reply to my question I assumed that he had no interest and so I turned my attention back to John. After a minute or two I realised that I had lost Sean.

My reaction was one of momentary panic when I saw Sean queuing near the top of the ladder. "*There was no way on earth*", I recorded in my field notes (day 14- 02/07/2010) "*that I would have allowed Sean to go up there alone, assuming as I did that he would not have had the patience to remain in the queue for what took over 5 minutes.*" What terrified me most of all however was what he might be liable to say to those around him and how he may (or may not) respond to safety instructions from the lifeguard at the entrance to the water slide. However, after a minute or two, I realised that my worries were completely unfounded. Sean conformed to the situation just like every other person in the queue, and it was clear by watching him talking to the little girl next to him that she was enjoying the conversation, whatever it was about.

Choice, purpose and control

Choice and self-confidence

According to Sean, "*I'm bad at making choices, especially hard ones*" (Field notes- day 4- 11/06/2010). As Sean's mother recently clarified (Planning meeting- 18/06/2011), this is because Sean has an overwhelming fear of making the 'wrong' choice. It is important to remember that Sean has had very little *experience* in making choices. His primary ABA

schooling was, and current post-primary schooling has been (which I myself am responsible for) extremely structured, wherein pupils follow a fixed daily schedule which is not always conducive to choice. Similarly, as Sean's parents explained (Interview, day 31) he had never, prior to the period of our fieldwork, been challenged to make significant decisions or choices in relation to himself. And as Noreen further reflected in a conversation that I had with her (at time of writing) only yesterday (20/07/2011), Sean's lack of confidence in making choices and decisions is unsurprising in light of the fact that his long-running ABA-based education constantly reinforced an imposed notion of what is 'right' and what is 'wrong' based upon decisions that were never made by Sean himself, but exclusively by others.

Yet, it is not that Sean cannot make excellent choices. It is rather that *he drastically lacks confidence in his own ability to make them*. This is despite the fact that, throughout the course of the fieldwork, whenever he was challenged (or almost pushed into) making a choice, he *always made a good choice* and could (when further pushed) always provide a remarkably candid justification for the choice that he made.⁴⁴ In addition, he is perfectly capable- when encouraged- of advising others upon what choices and decisions *they* should make.⁴⁵

What is additionally noteworthy to add is that, despite Sean's ongoing insistence that, again, "*I'm not good on real choices...well hard ones*" (Field notes- day 14- 02/07/2010), not only does he succeed in making excellent choices when pushed, but he responds *amazingly positively* to choice. In relation to the issue of choice generally, it's as though he initially fears it but relishes it when he is encouraged to place trust in his own ability to make 'good choices'. And in terms of general, everyday communication, when the element of choice is present, Sean's desire to communicate soars dramatically because, I posit, he is then involved in a *shared, democratic process* that is in itself, I further posit, a fundamental pre-requisite to the generation of shared control and meaningful communication.

⁴⁴ For instance, on day 23, when I asked Sean which McDonalds restaurant we should visit (Cork City or Douglas), despite his initial insistence that he couldn't make this choice- when pushed- he came up with an excellent justification for visiting the latter restaurant in Douglas. The Douglas restaurant, he explained, was recently "*done up and looks nicer*" (Field notes- day 23- 20/07/2010).

⁴⁵ On day 4 for instance, during our return journey to Sean's home I asked him what I should do over the weekend. I explained to him that I had cancelled a night out with a friend the previous weekend because I felt too tired to go out. I further explained that my friend, who was very annoyed about this the previous week, had forgiven me, and asked me to go out this weekend instead. I told Sean that I was very tired and didn't know what I should do. I told him that I had 2 options; stay in and rest (which would disappoint my friend but please me) or go out to meet my friend despite being tired. Sean replied in extremely articulate fashion; "*choose the second option because the first option is both lazy and selfish*". I was genuinely astonished with this response, the candidacy of which I had never heard from Sean before (Field notes- day 4- 11/06/2010).

Thus, from the third day of our fieldwork onwards, it became paramount to encourage Sean to make choices in our day-to-day activities.⁴⁶ This was done on a daily basis, in relation to numerous small, even seemingly insignificant decisions such as what coat he should wear, where we would go for lunch, what ‘Westlife’ song we would listen to in the car, the order in which we would listen them, the order in which we do planned activities etc. The key point to be made here is that it was possible to *maintain an external structure while creating the scope for Sean to make choices and decisions within it*. Such were simple choices that we naturally extend to peers, friends, or people who we may hardly even know, simply out of mutual respect, basic common courtesy, and an acknowledgment of the fact that anything even resembling a functional relationship must be a two-way interaction with choice and compromise forming its basic foundation.

The outcomes of encouraging choice

As I noted on day 10, “*as the fieldwork evolved, it became increasingly apparent that the more Sean was encouraged to make choices, such as how long to stay on the beach, when to go for lunch, when to go home, the more willing he became to step out of his comfort zone and the more open he became in communicating very naturally with me*” (Field notes- day 10- 21/06/2010). And this had a ‘knock-on effect’ on his general social behaviour, or what I will refer later to as ‘social conformity’.

It is interesting, in retrospect, to contrast Sean’s behaviour during our 2 shopping trips, on days 4 and 20 of our fieldwork. Exactly one month previously to day 20 Sean couldn’t cope with a shopping trip to Cork City when he didn’t know *exactly* where he would be going from one minute to the next, wanting nothing more than to go to 1 game shop, and “*having a pretty dramatic tantrum when we couldn’t find it*” (Field notes- day 4- 11/06/2010). Yet it should be noted that Sean’s reaction was most likely so contrite due to the fact that he was simply following me around from shop to shop and was not actively making any choices or decisions in relation to where we should go⁴⁷.

⁴⁶ Writing on day 20, I reflected that “*it’s by getting him to see that he is good at making small choices that he will build up the confidence to make more significant choices in his own life*” (Field notes- day 20- 12/07/2010).

⁴⁷ That said, when he met a number of my family and friends (I brought him to these shops to introduce him to new people) he remained very courteous.

However, exactly one month later, by day 20, I reflected in my field notes, “I [had] a *completely different boy in terms of behaviour, a boy completely willing to ‘go with the flow’, a boy impeccably behaved, displaying none of the rigidity he displayed one month previously. He never once became impatient in shops and in fact chatted politely with sales representatives etc*” (Field notes- day 20- 12/07/2010). On day 20, Sean quite happily went to a number of stores and *he chose* the order in which we went to them⁴⁸.

The importance of purpose

A further factor that differentiated our shopping trip on day 4 from that of day 20, in addition to the ‘choice factor’, was that of *purpose*. On day 4, there had been no stated purpose to our shopping trip. Day 20, in contrast, was all about preparation for our Carrauntoohil climb. On day 20 we visited at least 15 different stores shopping for flags, boots and climbing clothing, and Sean wasn’t in the slightest bit put out by visiting multiple stores until we found exactly what we were looking for. For instance, he tried on- without a word of complaint (which amazed me)- a number of items of clothing and hiking boots until he found the right types and fit for these (Field notes- day 20- 12/07/2010). Sean, I began to realise, invariably responds best to activities that *have a point to them* and invariably resists activities which lack purpose.

Perhaps this explains why, on day 2, Sean didn’t respond positively to climbing on the artificial climbing wall in the Mardyke Arena. In addition to his fear of heights (which I only subsequently found out about on day 10) his ascent of Carrauntoohil, on day 29, demonstrated that if Sean is going to put himself through strenuous activity *there must be a point to it*. On day 19, for instance, our golfing outing illustrated how Sean simply could not see a point to spending time fruitlessly attempting to put a ball into a hole (Field notes- day 19- 09/07/2010). He will apply focus to challenging activities only when there is an *identified*

⁴⁸ It is interesting to note that when Sean’s mood is positive he tends to draw attention to the ‘beautiful’ things in his immediate environment. Conversely, when he is stressed he becomes distressed by the ‘dirtiness’ of his surroundings (Field notes- day 20- 12/07/2010). On day 4, for instance, during our first shopping trip throughout which Sean was very stressed, he continually persisted in drawing attention to the rubbish (or what he calls ‘trash’) on the streets (Field notes- day 4- 11/06/2010). Yet on day 20, in complete contrast, during our second shopping trip, throughout which Sean remained focused and determined, instead of being critical of the dirty urban environment surrounding us, he chose to draw my attention towards many pretty things that he could see in the urban environment surrounding us, such as some pretty shop fronts and a FOTA Wildlife Park van parked outside ‘Maher’s Sports’ on Patrick’s Quay (Field notes- day 20- 12/07/2010).

purpose to the activity in question. The importance of purpose often also underpins less typically ‘challenging’ activities such as shopping. He will respond even more positively to shopping (than he did on day 20) when the *stated purpose* of the activity is to purchase a gift for another that, *it is explained to him*, will bring joy to its receiver, albeit the element of panic does often present itself as Sean invariably questions his ability to choose a gift for another that they might like.⁴⁹

The ‘transformative effect’

Person centred planning

On 18/06/2011, upon the request of Sean’s parents, I hosted the first of a series of ‘person centred planning’ meetings in Sean’s home. This paradigm, often referred to as a ‘support model’ or ‘ecological approach’ focuses on community membership and functional supports to enhance quality of life (Sanderson, 1998). According to the National Disability Authority (2009) person centred planning seeks, 1) to craft a vision for a person’s life as part of their local community and/or the broader mainstream of life, and 2) to describe the actions needed to move it in that direction, by mobilising and involving individuals’ entire social network as well as resources from the system of statutory services (NDA, 2009).

Following an examination of my edited field notes (which I had provided John and Noreen with a copy of) they assembled a team of 15 individuals, including many of Sean’s uncles and aunts (from both sides of the family), as well a number of their partners, to commence a planning initiative for Sean in which each individual would take Sean out into the community to engage in a series of activities. Essentially, this meeting involved taking the participants through the field notes, making suggestions and answering questions in relation to the nature of activities that, I believe, Sean responds to most optimally.

⁴⁹ On day 4, in ‘Dunne’s Stores’ (Field notes- 11/06/2010) I suggested to Sean that he might purchase a gift for either his mother or his father. When I quizzed him on *what he thought they might like*, after an initial phase of panic out of uncertainty, he eventually replied that he would like to buy his mom a ‘beautiful dress’ and his dad a ‘handsome tuxedo.’ Eventually, we settled upon purchasing a candle for Noreen. Writing up my field notes on day 11 I reflected that “*while buying gifts for people isn’t something that tends to occur to Sean he enjoys the process, and especially the giving of the gift, when he is helped choose it, and when it is explained to him that the gift will bring joy to the receiver*” (Original field notes- 11/06/2010).

The message that I felt was particularly important to transmit at the meeting was the importance of establishing a *balance* between activities that involve challenge and risk with those that involve *mutual* relaxation. This, I feel, is important to make the programme enjoyable and *sustainable* for both Sean and the programme participants.⁵⁰ In order to attempt to contextualise where I was coming from at the meeting, I drew close attention to my field notes from day 21.

Developing a sustainable planning network

Of the many milestone experiences that myself and Sean went through over the course of our 2 months together, I explained- from sailing a yacht to standing on the top of Carrauntoohil- there was one experience that clearly stood out in my memory above all others. This experience was recorded on film in ‘O’Briens’ cafe in Wilton Shopping Centre on day 21. The film clip is unremarkable on the surface. It shows Sean drinking his orange juice, reading his ‘Simpsons’ comic, happily reading and pretending, intermittently asking questions and making comments about things that interest and entertain him such as when “*Ted jumped through the window*” (Field notes- day 21- 13/07/2010).

The significance of this, I continued, was to acknowledge that on day 21, for the first time in the course of the fieldwork, I realised that *I needed to relax*- I reached a point where I needed to take time to read the newspaper in the comfort of *my own thoughts* as much as Sean needed time to read his ‘Simpsons’ comic in the comfort of *his own thoughts*. This is the reality of relationships I suggested to the planning committee; no person can give 100% of themselves all of the time. For any relationship to be sustainable there must be times factored in when both parties can simply relax in one other’s company without any demands being placed upon either person (Field notes- day 21- 13/07/2010).

Day 21, I further explained, was the first time when I further realised that any person who was to step into my shoes- be they Sean’s brothers, an uncle or an aunt, or whoever, could never sustain, *all of the time*, the level of activity and challenge that I set for myself and Sean over the course of the 2 months of fieldwork. What is needed, I suggested is *balance*, where

⁵⁰ For instance, Sean’s Godfather, Chris, asked if what we are setting out to do should primarily be an ‘educational programme’. Sean’s mother replied however that she saw it more as a programme designed to maximise Sean’s quality of life based upon the findings of the research project (Planning meeting- 18/06/2011).

the needs of the 'other' are taken into account also. In this regard, it was important to highlight that this experience shared with Sean in the cafe on day 21, something relatively easy to achieve and non-demanding upon both parties, was, in its own right, as significant an experience as climbing to the summit of Carrauntoohil. The short clip shows Sean deeply relaxed and happy, comfortable in his own skin, expressively being himself and (significantly in my view) almost playing to the camera (Field notes- day 21- 13/07/2010).

One may suggest that were one were to compare Sean's relaxed behaviour in 'O'Brien's' coffee shop on day 21, to the tantrums he displayed on day 4 (in Cork City) and day 11 (in Cobh), that he appeared to be somewhat 'transformed' by day 21. This would be an inaccurate assessment however. He was the very same Sean on days 4 and 11 as he was on day 4, or any other day. And he is exactly the same Sean today. The 31 day period of fieldwork should not be viewed within the context of some sort of 'therapy programme', whereby the intention would be to 'fix' the client. My approach entailed a very deliberate departure from traditional practices of programme delivery and assessment which exists within the field of special education in Ireland wherein; 1) you assess the child, 2) you run your programme, and 3) you reassess the child, looking for some evidence of improvement.

My intention was never to start off on day 1 with the 'autistic' Sean, with some deterministic intention to show that by the time we reached day 31, I could present a 'less autistic' Sean. Such an approach would, in my view, have amounted to nothing of any real value for Sean (and would, in fact, have been entirely disrespectful towards him). I never set out to 'transform' Sean. I just set out to understand him. Yet there *were* 'transformative moments'- for both of us.

The 'transformative effect'

On day 8, horse riding instructor, Mr. Jason Carey, described an experience he had working with a young girl with autism. "*She wouldn't talk to you*", Mr. Carey explained, "*but sit her on the horse and next thing the language is perfect, and for a couple of hours afterwards she's as right as rain, and then she starts to drift back in again you know*" (Interview- 17/06/2010). Similarly, during my interview with Mr. Corin Morgan Armstrong, he described Tae Kwon Do as having a 'transformative effect' upon his 21 year pupil with autism (Interview- 24/07/2010). Yet, as we have seen, as an activity, Tae Kwon Do had no appeal

for Sean (although Corin did). Similarly, while Sean cares for horses and other animals, he does not have any particular interest in them. So what does this suggest? It suggests to me that what appeals to the interests of one person with autism may not necessarily appeal to those of the next person with autism simply because they both have autism. What brings about a ‘transformative effect’, or what constitutes a ‘transformative moment’, will be just as random for an autistic person as it is for any non-autistic person.

Excitement and communication

If I were to apply the term ‘transformative moments’ to my experiences with Sean, they have tended, as I have already touched upon, to come about when the ingredients of choice, challenge and control are present. Yet this was not always the case. On day 9, for instance, following our viewing of ‘The Two Dimensional life of Her’ at the Granary Theatre, what particularly struck me was the surge in Sean’s enthusiasm to communicate *following the performance*, both during our walk back to the car, and throughout our journey back to his home. “*The point to be made here*”, I recorded in my field notes, “*is that it is not the activity itself, but rather the excitement that the activity generates, that appears to stimulate Sean’s drive to communicate after an activity has ended*” (Field notes- day 9- 18/06/2010). On this occasion Sean happily discussed many issues with me as we strolled away from the theatre, past the university, and back to the car with a fluency and naturalness that I had not, previously to this, experienced with him. Our conversation included the origin of what I suggested was his ‘American accent’ which, correcting me, Sean explained is actually “*American English*” which he explained “*I got from a bunch of movies, shows, you know that type of thing*” (Field notes- day 9- 18/06/2010). I distinctly remember this as being the precise moment when some sort of threshold was crossed between myself and Sean and we had, for all intensive purposes, become friends. This was *my* ‘transformative moment.’

Yet, in my view, the most powerful ‘transformative experience’ occurred after the ‘Westlife’ concert on the night of day 17. Upon the night in question, what was very noteworthy was not only the ‘transformative effect’ that played itself out during the concert itself, but the surge in Sean’s communicative drive after the performance had ended. “*During the 30 minute walk back to the car following the concert,*” I noted, “*Sean appeared to me to be completely unautistic*” (Field notes- day 17- 07/07/2010). Similarly to the walk back to the car from the Granary Theatre 8 days previously, a remarkable fluency came into Sean’s speech- generated

by a powerful *eagerness to communicate*, yet on the occasion following the ‘Westlife’ concert it was not only a 2-way conversation between Sean and I, but a 3-way conversation between Sean, his mother and I. And, on this occasion, he appeared to be even more animated than he had been on day 9. Conversation varied fluidly between the Cold War, his upcoming climbing trip to raise money for the poor children of Russia, as well as recalling a time when his mom tripped while chasing him across the road while on holiday in Lanzarote when he was 10 years old.

The ‘transformative effect’ versus sustained social experience

The reservation that I have with using the term ‘transformative effect’ is that it seems to imply some sort of ‘miracle moment’ wherein the autistic person temporarily disengages and departs from the world of autism, and then, when the transformative stimulus is removed, retreats back into their world of autistic aloneness. Granted, this may well be the case for some people. I am in no position to either accept nor reject such a hypothesis since such a hypothesis applies, intimately, to individual people. However, as a hypothesis goes, I suggest that it fails to go far enough in taking account of the crucial role of *sustained social experience* and the development of trust between individuals.

When I was initially writing and reviewing my field notes on a daily basis, I was focusing upon the ‘major’ events; the days in which Sean was set major challenges, those which I speculated had the power to ‘transform’ him, push him and develop him. I was constantly looking for the ‘next big thing’. There were additional challenges which I had hoped to set for him, but which due to logistical problems, never transpired. These included windsurfing, driving an actual car, and getting him flying lessons. And when these planned activities fell through I became extremely frustrated. However, having had the benefit of a full year to reflect upon my field notes and video footage, I came to realise that it was not the major challenges alone, such as yachting and mountaineering that, in isolation, contributed to the communicative surge in Sean that his parents and I witnessed over the course of 2 months. Rather it was, I suggest, *the continuum of sustained social experience* that brought this about. The major challenges, and the major accomplishments, were in themselves hugely significant but they would not, in my view, have amounted to anything significant *in isolation*. To use a colloquial expression, it was not just the big things but, rather, a combination of the big things with all of the little things that ultimately counted.

Yet it was, for me, difficult to really ‘see’ this until I had a significant amount of time to ‘live with’ and reflect upon the entirety of the research experience. The significance of apparently minor experiences was often lost on me at the times when those experiences occurred. It took a very lengthy interim period of reflection and re-reflection, analysis and re-analysis, of not only the data itself, but also my own personal engagement with that data before a new subliminal subtext inherent within the data began to reveal itself. And this subtext, which is what I can only describe as an almost invisible thread which runs through the nature of lived experience buried deep within the data, eventually revealed the true nature of Sean’s ‘transformation’ or what, perhaps, should be more accurately described as- simply- his progress. One such example has already been described, that of the experience that Sean and I shared on day 21 in ‘O’Brien’s’ coffee shop. But many more such ‘tiny little leaps’, to use an oxymoron, were taking place daily, albeit they were completely unbeknownst to me at the time.

Take for instance day 23, when we went swimming in ‘Leisureworld’. Day 23 was the very first time when Sean, after 2 years of visiting ‘Leisureworld’, demonstrated the confidence to approach Joanne, the lifeguard, to say hello to her (Field notes- day 23- 20/07/2010). Similarly, day 24, in ‘Costa’ Café, was one of very few instances wherein I witnessed Sean to spontaneously and independently strike up a conversation with a complete stranger (a man who, as we casually sat there sipping our drinks, I mentioned to Sean I believed I knew from somewhere, but couldn’t remember exactly where) by offering the man a hand shake, fastening up the buttons of his suit jacket (Sean always does this whenever he sees somebody wearing a suit), asking what his name was, and how he knew me- “*exactly*” (Field notes- day 24- 21/07/2010).

The assessment of progress

The benefit of hindsight

On day 14, I recall feeling distinctly annoyed that Sean refused to engage with his classmate John throughout the duration of our visit to ‘Trabolgon’ swimming pool & activity centre. Nonetheless, on the evening of day 14, I typed the day up, switched off my laptop, and wrote it off as a ‘bad day.’ Yet, when I reviewed the field notes from day 14 sometime later, and really *thought about* what had happened on that day, it became obvious that Sean had taken

another huge leap forward but that, for no reason other than sheer annoyance, I had entirely failed to recognise at the time.

On day 14, I had recorded in my field notes; “*during our return journey from Trabolgon to Cork there was no doubting that Sean was becoming ever more chatty and observant of his surroundings. In addition to random questions and statements such as ‘were Westlife ever on an Irish song competition, Jedward were’... ‘I just saw a car’... ‘what do you picture them [the clouds] in...I picture one of them as a shark’*”. As Sean gradually won my annoyance over he happily responded to my questions as we drove through the picturesque town of Whitegate, calling it a “*nice town*” and commenting that the seaweed “*smells nice...like sand*”. Meanwhile he was asking numerous questions about “*the woman*” on the ‘All out of love’ ‘Westlife’ track, and was later quite moved when I played the track ‘The Dance’, which with an emotionally charged facial expression, he professed is “*not too bad actually*” (Field notes- day 14- 02/07/2010).

Reconceptualising ‘milestone’ and ‘subliminal’ progress

When one is engaged in this type of exploratory fieldwork, I suggest, it is easy to gauge ‘progress’ in relation to the outcomes of ‘major challenges’. These are times when the researcher sets challenges for ‘the researched’, which the researched then either fails or succeeds in achieving. Thus, days such as day 5 (yachting), day 16 (karting), day 17 (the ‘Westlife’ concert) and day 29 (the ascent of Carrauntoohil), which may perhaps be described as ‘milestone days’, may well have formed the initial pillars of analysis but could in themselves, never tell the full story.

It would be deceptively easy to identify such milestone days as being days constituting accomplishment in its global entirety and therefore, by implication- progress in its global entirety. This is because *subliminal progress* is something that is much more difficult to recognise in the first instance, or to quantify in the second instance. Nonetheless, this subliminal, almost invisible, progress was taking place all of the time, albeit the only way that I could attempt to describe it was by noting, in passing, the subtle changes that were taking place in Sean’s global *demeanour* as these appeared to me over time.

These changes in Sean's demeanour had first struck me most powerfully on the morning of day 16, in Douglas Court Shopping Centre, prior to our departure for Watergrasshill Karting Centre. In my field notes I recorded that "*Sean's interest in the new large flag hanging in Douglas Court shopping centre was not only a reflection of his interest in flags and symbols generally, but was another example of how much more interested in his surroundings he is becoming and how much more alert he seems generally*" (Field notes- day 16- 06/07/2010). As I watched Sean strolling, in carefree fashion, around the shopping centre before our departure to Watergrasshill, I was genuinely dumbstruck by the extent to which his demeanour, his attitude, his body language, his generation of and response to conversation, his observation of his surroundings, and his general outward sense of happiness had improved a great deal in what was a very short period of time (Field notes- day 16- 06/07/2010).

Social experience and social conformity

And accompanying these changes in Sean's global demeanour, from the rigidly resistant to the flexibly optimistic, came giant leaps in what one may term (for the want of a better expression), 'social conformity'. I have already briefly touched upon this issue by contrasting Sean's behaviour during our second shopping trip in Cork City on day 20 with his behaviour during our first shopping trip on day 4. Yet there had been an even more powerful example, if somewhat of a different nature, that had occurred on day 9 during the performance of 'The Two Dimensional Life of Her' at the Granary Theatre. "*This was*", I noted in my field notes "*one of the finest examples of a very demanding social situation I have seen Sean conforming to in terms of maintaining attention, conforming to a shared (difficult) behavioural norm, and controlling fear.*" "*I wouldn't*", I conceded, "*have expected Sean to manage any of these prior to the performance. There were merely 20 people in the audience, seated in 4 rows at the very edge of the performance area (which was not on a stage but on a level platform with the performers) in considerable darkness. The situation demanded that audience members remained completely silent, and completely still, for the entire duration of the performance*" (Field notes- day 9- 18/06/2010).

"*I was surprised*", I went on, "*that Sean did not ask to go to the bathroom which he normally would do very frequently as, I am certain, he was very much aware that this would have interrupted the performance*" (Field notes- day 9- 18/06/2010). He clearly understood that he was part of a shared, *adult* social experience that demanded social discipline. In other

words, *he showed a clear ability to comprehend the mental states of others*. Further evidence of this came during an illusion of fire when the entire theatre appeared to go up in flames. I was astounded, given Sean's extreme fear of injury and death (which I will discuss later), that he did not panic. By all accounts he should have panicked. The only possible explanation that I can offer as to why he did not panic is that he observed that nobody else around him was panicking and, from that, deduced that there was no real danger to himself or others (Field notes- day 9- 18/06/2010).

Subliminal progress

This experience in the Granary Theatre, on day 9, was one of those 'major milestone moments' when Sean displayed skills of social conformity which he had not (at least in my company) ever previously exhibited in the past. Again however, in retrospect, there were clearly many more subliminal displays of flawless social conformity on Sean's part continually occurring as the fieldwork progressed. Take day 13 for instance, on the occasion our trip to the cinema to see 'When in Rome.' During the performance, in the darkness of the cinema auditorium, when I sat next to Sean whereupon he mistook me for a stranger, rather than panicking (which would, I am reasonably certain, have been the case in the past) he politely turned to me and said "*excuse me Sir, this seat is taken*" (Field notes- day 13- 01/07/2010).

Intrigued by this, following the performance as myself and Sean browsed around 'Eason's' bookstore in Mahon Point shopping complex, I deliberately slipped out of the store and, from an unobservable distance, watched to investigate how Sean would react when he realised that I had gone missing. When it dawned upon Sean that I was no longer within sight, rather than panicking, he calmly strolled around the store to search for for me. When I was nowhere to be found, he calmly returned to casually browsing about the comics section. Growing ever more curious, I allowed a few more minutes to elapse before returning to the store, fully expecting to be greeted with a torrent of retribution for leaving without warning (which definitely would have been the case in the past), only to be greeted by a calm and composed Sean who, with a rye smile on his face, simply glanced over his shoulder and said, "*Oh, hea Steve*" (Field notes- day 13- 01/07/2010). By the final day of our fieldwork (day 31) I had plucked enough courage to leave Sean alone in the 'Gamestop' store in Douglas Court Shopping Centre while I wandered off to purchase him a gift for his upcoming 15th birthday.

Increasing social independence and evaluating the risks

In light of the ‘major’ accomplishments that Sean achieved in the course of our fieldwork, such apparently ‘tiny’ accomplishments may appear to have been utterly trivial in nature. Similarly, my own need to pluck up enough ‘courage’ to leave Sean alone, unsupervised for a mere 15 minutes in a game store, may appear to have been utterly unwarranted. And perhaps it was. This brings us towards the issue of balancing the elements of protection and risk. And the elements of risk cannot simply be ignored. So what are these risks? Allow me to contextualise with reference to 3 examples.

Firstly, were Sean to witness somebody killing a fly, for instance, he could interject with an intensity comparable to as though he was witnessing somebody being murdered before him on the street. He displays *no fear* in his quest for ‘social justice.’ As Sean’s father John recounted at our recent planning meeting (18/06/2011), one week previously Sean had gone “*utterly ballistic*” when John accidentally killed a fly while attempting to remove it from the bathroom before Sean took his shower before bed time. In a torrent of tears and anger Sean scolded his father, shaking his fists at him, screaming “*what about that fly’s family, what about their feelings!*” Sean came close to pushing his father who had to calmly back away and encourage Sean to take what amounted to an hour to calm down. Later that night, as John checked in on his son in his bed, Sean lay there quietly sobbing, deflated and depressed, for all intensive purposes- heartbroken, over the fate of that fly’s family.

Secondly, were Sean to see somebody smoking he may approach that person and plead with them to stop. On a recent summer camp outing (28/06/2011) Sean, for the first time since I have known him, caught me smoking a cigarette, to which he responded with shock and anger, “*Steve you have to stop! You don’t want to end up like Aunt Liz! Don’t you know this!*” Reaching for the right pocket of my jeans he demanded that I remove my packet of cigarettes and, under his supervision, dispose of the packet in a nearby dustbin and- on top of this- promise him that I would “*never smoke again*” (Summer Camp outing- 28/06/2011).

Thirdly, were Sean to come across somebody using a wheelchair, somebody with a visibly noticeable intellectual disability such as Down’s syndrome, or anybody who strikes him as ‘needing his help’, he may be liable to say anything, which could be misconstrued as being

deliberately insulting. And, as it was explained to me 3 years ago by Sean's previous ABA tutor, no amount of 'social skills training' could ever rectify this aspect of Sean's behaviour.

We may call this 'theory of mind' or 'mentalising' deficit. Or we may call it being uncompromisingly principled. It makes no difference what we call it. The reality is that we are working with a young man who struggles, and who may always struggle, to see the world from anything other than his own utopian perspective. But does this mean that his independence should be forever curtailed for fear of how others may respond to him? My emotional response to this question is 'who cares what other people think.' My balanced response to this question is, however, that *we will never know how Sean will socially perform independently until we grant him, even if only very slowly and incrementally, increased opportunities for social independence.* And that is exactly what I suggested at our recent planning meeting in Sean's home (18/06/2011).

Increasing social independence- exploring the possibilities

Sean's family home is a mere 20 minute drive from the largest, self-contained shopping complex in the wider region of Cork City and County (Mahon Point Shopping Centre). And, within the relative safety of its walled confines, it houses almost everything that Sean loves. It contains a cinema omniplex, a 'McDonald's' restaurant, game shops, DVD shops, book shops (with all of the latest comics), and internet access points. "*What if*", I proposed at the aforementioned planning meeting, "*we could get Sean to the point where he could be dropped to the door of Mahon Point Shopping Centre, left to his own devices, and collected at the door a couple of hours later?*" (Planning meeting- 18/06/2011)

Immediately upon me making this suggestion a look came over Sean's mother's face that I had not seen since the day when I first suggested to her that we give Sean "*a go off climbing Carrauntoohil.*" And again, in this instance, I don't blame her in the slightest for her unspoken reluctance. Such a challenge is, in the wider scheme of things, monumental, considering *where Sean has come from.*⁵¹ Yet, I do *genuinely* believe that increased independence for Sean is something that is *absolutely possible to achieve.* We (and I

⁵¹ On day 13 of our fieldwork, for instance, I conceded that I was, "*in fairness, dealing with a boy who up to 7 months previously, it was felt, would not be able to manage in the back of a car alone without a minder*" (Field notes- day 13- 01/07/2010).

acknowledge & include Sean's previous ABA tutors in this) have brought him to a point where he can now independently work with money. He can now (almost) get across to 'McDonald's' staff his food order (which is complex in light of his restricted gluten-free, casein-free diet). He can read the cinema times and he will, at a push, wear a watch. He can operate a mobile phone, and although when it rings it tends to startle him, he could hold onto it and switch it on only in the event of an emergency.

And finally, in relation to the social risks that I have drawn attention to, I strongly suspect that Sean primarily goes 'ballistic' when the person involved in what he deems to be wrong is *somebody who he knows*. The fact is that we simply don't know as yet if Sean would pass say, an individual with Down's syndrome, without questioning him/her. Would he, if left to his own devices - in the interests of getting from A to B with the minimum of fuss- allow certain things to pass him by, particularly if through co-existing projects to help others, he could refocus his energy away from reactive displays of concern for others towards structured and consistent projects designed to help him help those less fortunate than himself?

I believe that he would. This is because I am confident that Sean could comprehend the following type of statement relating to himself; *'When I am in Mahon Point I am there to enjoy myself and look after myself. When I am doing my charity work, that's when I will help others.'* Essentially, what I am arguing is that instead of continuing in vain to attempt to extinguish Sean's 'inappropriate' behaviours, by alternatively redirecting and channelling his energy to be the 'good guy' who he so desperately wants to be, he could learn- over the course of time- to 'let the little things go' in favour of being granted *control and purpose* within schemes pertaining to a wider picture promoting social empathy and social justice.

Moving forward- the quest for evidence

As I have previously alluded to, giving Sean more freedom and independence is as a teacher, a parent, a family member, or a family friend- a truly terrifying proposition. As I have conceded, it requires sacrificing fear to faith and accepted 'knowledge' to the entirely unknown. It requires, to use a horse riding analogy, *little by little*- letting go of the rope. But for this to happen, I accept, that we need evidence. We need evidence to reassure ourselves that it has been demonstrated that the *person Sean* can win out over the 'autistic' Sean.

Perhaps though, providing convincing evidence to allay what are very natural and human concerns should, one may justifiably argue, be presented as part of a longitudinal study that extends beyond a period of 2 months. Yet all I can present is 2 months, and within that, only 31 days. These were 31 days punctuating a 2 month period of fieldwork wherein Sean never failed to astound me in terms of what he is capable of achieving when he is challenged, focused and in control. We shared a journey together, a wonderful journey. But is this enough? Is this enough to justify my claim to Sean's parents, and those who intensely love and care for him, that "*this kid, if challenged, is capable of achieving anything*" (Planning meeting- 18/06/2011). Had I the opportunity to 'shadow' Sean⁵² over a longer period of time it would be much easier for me to approach those who love him and state with both confidence and assurance that 'I have seen him do this- and it is safe.'

But this was not a longitudinal study. It cannot offer rigidly watertight, tested and re-tested examples of how Sean will respond and react to *every possible situation* to which he is exposed over a long-scale period of time. But what it can offer, I humbly suggest, are *exemplars* of what *it is possible* for Sean to achieve. We had yachting, karting, Tae Kwon Do, the 'Westlife' concert, the 'Mamma Mia' concert- many, many adventures that were previously considered to be completely out of range for Sean. But, then again, did these activities *really push him?* Did they *really challenge him?* Yes, I suggest, they did- but not to his limits. Many activities which I had assumed would be *major challenges* for Sean, experience showed, in fact sat very comfortably within his range of ability.

That is why Sean's ascent of Carrauntoohil was so significant. It is the most powerfully convincing piece of evidence that I can offer to defend my ascertainment that the *person* Sean has the power to overcome the 'autistic' Sean. This may resonate as an over-romanticised and over-sentimentalistic imposed dichotomy between the *person* on the one hand and the *disability* on the other. But it is not intended as such. As I mentioned to Noreen (at time of writing) only yesterday (20/07/2011), I wouldn't change Sean for anything. If the condition of autism has in any way contributed towards the purity and undeniable beauty of Sean's personality, then his 'condition' is clearly a powerfully positive force. The point that I am making is that *all of us*, regardless of whether or not we have a disability, are composed of a

⁵² This would involve 'shadowing' Sean in a number of different contexts and environments, making detailed notes upon the nature of the accommodations and teaching strategies that we may need to explore to ensure his optimal level of independence within these environments.

mixture of strength and weakness. That's what makes us *human*. Yet there are times, in all of our lives, when we are called upon, and *challenged*, to pit our strengths against our weaknesses. And when our strengths win out, that's what builds self-esteem and self-efficacy. And these are what build *self-confidence* and *self-belief*. And collectively all of these develop in us a sense of *optimism* and *purpose*.

I conceptualise 'Sean's Victory' on Carrauntoohil as representing the 'ultimate showdown' between his 'autistic self' on the one hand, and the power of his human spirit on the other. Carrauntoohil was the big 'tester' for Sean. And the odds were insurmountably stacked against him. Before I conclude this chapter by describing what actually happened on day 29, it is important, I believe, to briefly take a step back to examine some of the features of the 'autistic Sean', those which contributed towards the apparently insurmountable odds that were stacked so heavily against him, and then to juxtapose those with the background emergence of Sean's motivation and sheer strength of will that drove him up a mountain that he was never supposed to climb.

Facing challenge

The 'autistic' Sean

In addition to his difficulties in comprehending the mental states of others, I would identify the core features of Sean's persona that correlate most strongly with the impairments that we traditionally associate with autism, as falling into the categories of 1) severe hypochondria, 2) major physical limitations in terms of strength and endurance, and 3) a chronic inability to self-regulate time.

The power of hypochondria

Sean has displayed a plethora of irrational fears and phobias since I have known him. Many of these fears are recurrent, which as Sean's mother has explained to me, tend to come and go in phases in which they increase and decrease in intensity. Horse riding instructor, Mr. Jason Carey's testimony that "*what was his last fixation...it was the earth flipping and the whole lot in 2012, he was fierce upset and worried asking if the horses will be ok and what's going to*

happen” (Interview- 17/06/2010) was I suggest, as I noted on day 8, “*further evidence of the power that phobias can exert over Sean’s mind*” (Field notes- day 8- 17/06/2010).

Such phobias include:

- Fear that if he comes close to certain sprays (such as when passing a gardener spraying weed killer) he could die.
- Fear that if a foreign substance (such as ink from a pen) enters his bloodstream from the tiniest of scratches on his skin, again, he could die.
- Fear that if he were to consume too much ‘McDonald’s’ food he could die (Field notes- day 4- 11/06/2010).

Essentially, phobias can and do cause Sean *extreme fear and upset*. Perhaps this, on some level, may be explained with reference to the literalness with which Sean interprets narratives, in conjunction with the major difficulties that he encounters in relation to abstract language. On day 15, for instance, he revealed that his then recently acquired fear of ‘McDonald’s’ food originated from his viewing of a television documentary in which a man who ate nothing but ‘McDonald’s’ food for a number of months “*almost died*” (Field notes- day 15- 05/07/2010).

A further example of the very real distress which phobias exert over Sean’s mind manifested itself in September 2010, after he had viewed a documentary postulating the ‘end of the world’ theory- Armageddon, December 2012. In attempting to allay Sean’s fears it was impossible for me to successfully explain to him that while it *theoretically* could happen, the *likelihood* of it happening is extremely unlikely. The only way of extinguishing his intense anguish and fear was to tell him quite clearly that the story was in fact a complete lie ‘made up by the film makers to scare people just to make money’ (Field notes- day 4- 11/06/2010).

Fear of death

On day 19, upon being informed of my Grandmother’s age of 97 during our drive to her home, Sean asked in an upset manner, “*will she die?*” (Field notes- day 19- 09/07/2010). Sean’s mother subsequently informed me that in the past she had told Sean that people don’t

die until they are 100 in an attempt to allay his all-consuming fear of death. However, the passing of his aunt Liz clearly had a profoundly traumatic effect upon Sean. It generated feelings of resentment and anger towards his parents because (as Sean divulged during a 3 way communication session between him and his parents facilitated by myself in school on Thursday 17th March 2011) he knew that Liz might die but his parents said that she wouldn't die. In Sean's words, which were emotionally and pointedly directed towards his parents, "*why did you say this... I was right... unfortunately*" (Communication session- 17/03/2011). And despite my repeated reassurances in relation to the certainty of the existence of heaven, when I asked Sean "*where do you think Liz is now*" he simply replied despondently, "*in a grave*".

Sean's physical 'limitations'

Until our training hike in Gungan Barra, on day 25, I was well aware of the psychological challenge that an attempted ascent of Carrauntoohil would pose to Sean and I had worked on that from the point of view of seizing upon his desire to help others. However, I had not yet fully considered how the proposed ascent would challenge him physically, and what myself and Joe observed during this training hike on day 25 gave us both great cause for concern. The key problems that we could identify (in addition to weak muscle tone and general endurance) could be described as evidence of serious problems in relation to his vestibular and proprioceptive senses.

As mentioned in my literature review, the vestibular sense dictates the movement of the head in relation to gravity, while the proprioceptive sense relates to muscle tone and the sensations generated inside of the body which mark where the parts of the body are in relation to each other. The effect of this was that, during our training hike, Sean had to constantly watch and monitor where he was positioning his feet, even on only very moderately uneven surfaces and could not, as we normally do, walk along an even slightly uneven surface without having to constantly watch his feet and meticulously plan every step in advance. This made progress painfully slow and psychologically put Sean (as well as Joe and I) under a great deal of pressure. This prompted us to refocus our goal away from an ascent of Carrauntoohil to that of bringing Sean into the foothills of Carrauntoohil (Field notes- day 25- 22/07/2010).

Sean's physical strengths

However, following my observations of Sean's physical deficits on day 25 (22/07/2010), the assessment feedback that Mr. Corin Morgan Armstrong, Tae Kwon Do instructor, furnished me with during our interview (24/07/2010) provided me with a more positive take on Sean's physical *strengths*. The key most positive item of assessment feedback was that while Sean's upper body strength is extremely poor, his legs are strong.⁵³ This was significant feedback because lower body strength is a major physical asset when mountaineering. This strength may, I contemplated, get him at least *some of the way up* Carrauntoohil. Yet, there was one major concern still outstanding. This was Sean's chronic inability to self-regulate time which, I feared, would pose another major obstacle to us on the mountain.

Approaching the regulation of time

On day 26, during his Tae Kwon Do training session, Sean's insistence on constantly being told 'how long is left' annoyed me greatly, primarily because I was acutely conscious of the incredible efforts that Mr. Corin Morgan Armstrong (having travelled from the UK) had gone to in order to facilitate the session (Field notes- day 26- 23/07/2010). However, what transpired in my interview with Corin the following day was that my sense of annoyance was utterly unwarranted and was, in fact, quite unfair towards Sean.

As Mr. Morgan Armstrong, reflecting upon his session with Sean, explained to me, "*I mean it's a hard thing to do [Tae Kwon Do], even with completely able bodied and minded kids of his age...I think it's very, very common really [giving time parameters]. I mean teaching children whether they're somewhere on the autistic spectrum or not. I've been training twenty four years and sometimes my motivation when I'm training is very low...I'm thinking kind of 'are we there yet' ...and I think that's the same for anyone*" (Interview- 26/06/2010).

From that interview forth, I vowed that I would never again expect Sean to regulate time on his own during activities entailing strenuous levels of challenge. Mr. Morgan Armstrong's

⁵³ As Mr. Morgan-Armstrong explained, "*his legs were quite strong and he put some power behind his kicks... There didn't seem to be any power in his arms even though he's quite big for his age.*" It was also very encouraging that Sean did very well on the coordination and speed reaction tests administered by Mr. Morgan Armstrong who further reported that "*he had good reaction speed, good coordination and good focus as well...He was coordinated more so than I would say probably most people, be they children or adults or teenagers, in their first session of Tae Kwon Do*" (Interview- 26/06/2010).

comments in relation to the regulation of time were subsequently proven to be highly accurate within the context of the Carrauntoohil challenge, with highly structured time parameters (which Sean had the responsibility of ensuring the entire climbing team would adhere to) playing a critical role in the eventual success of the expedition. Yet this was further paralleled by an ever-evolving sense of optimism on Sean's part, based upon *challenge*, which led me to speculate that, despite the fact that Sean was well aware of the gravity of the mountaineering challenge that was imminently facing him, he seemed, quite curiously, to be somewhat looking forward to it.

Harnessing optimism

It would be reasonably accurate, I believe, to suggest that prior to our fieldwork exercise, Sean would not have presented as the type of person who would express that he was 'looking forward' to anything new (besides DVDs and video games). He tended to live very much in the here and now. As Sean's mother Noreen stated in her speech on the occasion of Sean's awards ceremony, December 14th 2010, "*for anyone who knows Sean they will know that he loves his video games, and he loves his DVDs, and he really doesn't like being outside, at all.*"

However, when Sean was informed that he would be going to see 'Westlife' in concert, for instance, and in particular how he would be going as a VIP because Nikki Byrne from the band *heard about Sean* (which he did) and gave him the tickets (which he also did); from then on he began displaying a genuine sense of forward-looking optimism by asking lots of questions about 'Nick from 'Westlife' who *knew of Sean*, as well as the other band members, regularly asking "*how long is left before we go to Westlife?*" The same was true in relation to his ever-impending Carrauntoohil challenge, driven as he was to find out as much additional information as possible about Pat Falvey and Joe O'Leary (particularly in terms of their exact climbing credentials) because, (quite smartly in my view) on one level he wanted to double check that he would be reasonably safe, but most importantly, because by now he felt a human connection with Pat and Joe, who just like his friend 'Nick' from 'Westlife', took a genuine interest in him (Field notes- day 13- 01/07/2010).

Trust and the power of motivation

There are 2 critical points to be made here. The first point is that a crucial ingredient in the success of the Carrauntoohil expedition was that an established foundation of *trust* had been built up over time between Sean, Pat and Joe. As Mr. Brendan Murphy put it in the course of his speech at Sean's awards night, following the public screening of 'Sean's Victory' DVD; *"I think that what has happened here is that Sean has learned to trust. I think you could see that trust as he went up the mountain. He trusted all those around him. And he learned to do that and he knew that when he trusted that he'd be alright. As a result of that, he learned to take risks, because that's the context in which you can take risks, and without taking the risks, you can't achieve your dreams."*

The second point is that, unlike many past events in Sean's life, some of which I suggest may have been like fleeting, insignificant moments disconnected in time and space, *he fastidiously clung onto the challenge of the Carrauntoohil climb*, retaining it in memory, psychologically preparing for it in his own way- quizzing, investigating, questioning- using every possible tool at his disposal to psychologically prepare himself for the challenge confronting him.

But where did this emanate from? What had planted a seed of determination in Sean's mind, one so charged, so electrified, so strong, that it had the power to drive him up a mountain that drastically exceeded the assumed thresholds of his physical and mental endurance? It originated, in fact, from nothing more than a very simple, everyday act of communication which took place upon our return journey from Inchadonny beach to Cork on day 10 that set in motion a chain of sequential events that ultimately made the seemingly impossible-possible. The following is an extract from the conversation which I had with Sean (recorded on Dictaphone), upon our return journey from Inchadonny to Cork. The dialogue, I suggest, speaks very much for itself.

Sean: What happened to Russia after the Cold War?

Steve: The country became very poor. It has a very poor economy. I was in Russia in 1998 and it was still very poor then.

Sean: Is it still poor now?

Steve: It is very poor still ya. Parts of it more so than others.

Sean: Why can't we just find a way to help them? All the good people in Russia.

Steve: Do you know for your Carrauntoohil expedition when you are going to climb the highest mountain in Ireland. When you do that you can raise some money for a charity. You are going to put the Irish flag on top aren't you?

Sean: Yeah.

Steve: And what other flag are you going to put on top?

Sean: The European Union and the other one.

Steve: What other one?

Sean: Maybe the Russian one. Do you think you could help the economy of Russia?

Steve: I think what you should do is get a sponsorship card. That way you could get people to sponsor you money. For taking on your heroic feat people will give you some money. You could then send that money to help poor people in Russia.

Sean: So if we get the money we can make the economy of Russia a bit better, am I right?

Steve: You are exactly right. Do you know who would give you some very good information on Russia- Pat Falvey and my dad Joe cause they were with me in Russia in 1998. We were there for about three weeks and at that time we were there the value of the Russian currency halved which basically meant that their money was worth very, very little. So lots of people were in fierce poverty in Russia.

Sean: So then we're gonna have to go to the highest mountain in Ireland. Hopefully it won't be a snowy one right?

Steve: No it's not a snowy one. It will be a lovely warm day. Pat Falvey and Dad will have you on ropes so if you slip they'll catch you. Now it won't be easy. It will be a challenge but I certainly think that you could do it.

Sean: I don't know. I'm afraid of heights.

Steve: We are going to go up a way that's not too steep at all.

Sean: How long will it take?

Steve: It will take about three and a half to four hours to get up and about two hours to come down. So if we leave at ten o'clock we will be finished for about four o'clock.

Sean: Four o'clock. When are we going?

Steve: We'll be going probably some day next week.

Sean: What about the Russian military? Is it poor?

Steve: Yeah.

(Field notes- day 10- 21/06/2010)

Sean's subsequent fundraising effort raised 725 Euro through sponsorship for the charity 'Chernobyl Children International'. The funds were deployed to the Vesnova Children's Orphanage in Belarus. A letter of acknowledgement from 'Chernobyl Children International' (16/12/2010) commending Sean's "*decency and sense of purpose*" is included in appendix O.

The ascent of Carrauntoohil

Ethical and safety considerations

At 7.00 am, on Wednesday July 28th 2010, Joe and I arrived at the Cronin's family home to collect Sean. Upon our arrival, Noreen talked myself and Joe through the range specialised foods and fluids that she had packed for Sean.⁵⁴ After our departure, as Joe, Sean and I made our way from Cork to Kerry, Joe and I continually reassured Sean that *he did not have to make it to the top of Carrauntoohil*. We explained that it was a very demanding mountain that most people fail to summit on their first attempt. In our pre-expedition briefings Joe, Pat and I had agreed that while we would push Sean close to his limits, we were not, under any circumstances, going to push him beyond them. The *one thing that we were definitely not going to do*, Pat had made it clear to me when I initially pitched the idea to him in early June 2010, was end up in a situation where we would have to call in a full-scale mountain rescue which would involve Sean being air lifted off the mountain. In fact, only one week after Sean's summit of Carrauntoohil via the 'Devil's Ladder' route, a climber was air lifted off the ladder when he and his team ran into difficulty. Carrauntoohil, Ireland's highest peak standing at 3,414 feet, is a very serious mountain regardless of whichever route a team selects to pursue towards the famous steel cross perched upon it's summit. Carrauntoohil has claimed numerous lives over the years, some of whom have been close personal friends of both Joe and Pat. Yet, on the other hand, I had a seriously professional duo of climbers leading the expedition.⁵⁵

⁵⁴Noreen, being a medical nutritionist, had calculated the approximate number of calories that Sean would most likely burn up during the 8 to 9 hour expedition and then, as a precaution, provided us with enough food and fluids to fuel Sean with double that amount of nutritional energy.

⁵⁵ Joe O'Leary and Pat Falvey are both professionally trained, highly accomplished mountaineers and high-altitude climbers with years of experience in mountain rescue. They have both over 30 years experience on some of the most dangerous and inhospitable mountains on earth. Joe has two ascents of Kilimanjaro to his credit as well as having acted as a professional guide on a number of Pat's expeditions in the Russian Caucasus, Africa and the Himalayas. Pat Falvey is Ireland's most accomplished mountaineer and Polar explorer. He has over 50 ascents of the highest mountains on earth to his credit. He is the only Irish climber to have summited

And yet, when I rang Pat to initially pitch the idea of Sean's attempt on Carrauntoohil in June 2010, he was very apprehensive. The difficulty, as he explained it to me, is that *you can't make a person want to climb a mountain*- that must come from the person themselves. It was not until I approached Pat again later that month, after my conversation with Sean upon our return journey from Inchadonny to Cork (Day 10, 21/06/2010) and told him of Sean's desire to raise money for "*all the good people in Russia*" that Pat began to see a glimmer of hope. Mountaineering, Pat explained to me, is all about *motivation*. If Sean was truly motivated, he assured me, he would accept the responsibility. But, he made it equally crystal clear to me, that if Sean *once said* that he wanted to do back down, he was taking him back down.⁵⁶ As Pat made it clear, if there was any danger that Sean would *psychologically* collapse at any point on the mountain, he would be brought back down before that psychological collapse had the opportunity to lead to physical collapse which, leaving the seriousness of a full-scale air lift off the mountain aside, would leave an extremely damaging, long-term psychological effect on Sean.

This is why as we made our way from Cork to Killarney, Co. Kerry, and in through the rugged foothills of Carrauntoohil, myself and Joe kept reminding Sean that *he should only go as far as he wanted to go*. And as we neared Carrauntoohil, the sheer enormity of it coming into focus, and Sean asked me that- if he were to fail, the "*poor children of Russia*" would still get the money, I assured him that "*of course they will.*"

Balancing data collection with safety considerations

'Sean's Victory' DVD vividly tells the story of Sean's monumental achievement in reaching the summit of Carrauntoohil at 2.50 pm on Wednesday, July 28th 2010. For this reason I will not present a detailed chronological description of the climb. While I captured a reasonably extensive amount of video footage during the ascent of Carrauntoohil, there is very little

Mount Everest (29,035 feet) twice; from both Nepal (in 1995) and Tibet (in 2004). He is the only climber in history to have summited the 7 highest mountains on the 7 continents of the world not only once, but twice, taking Mount Everest from both her east and west sides, in the process leading Dr. Clare O'Leary, the first and only Irish woman to summit Mount Everest, to the top of the world in May 2004, before going onto lead the first and only successful Irish expedition in history to the South Pole in January 2008.

⁵⁶ This was why I was so fortunate to have one of the world's leading mountaineers advising me on this challenge, one who has not only achieved historic feats of skill, courage and endurance, but one who has also lived to tell the tale. *Safety* was of uncompromising importance. Every technical safety precaution possible would be taken, in terms of specialised equipment, support climbers and logistics.

footage of the decent off the mountain due to the seriousness of the descent which required all of our team's collective attention to the task at hand.⁵⁷

Perhaps an avenue worth pursuing towards providing a written picture of what transpired during the ascent and decent of Carrauntoohil on day 29 would be to revisit the interview data provided by Mr. Pat Falvey, on the evening of day 29. Before I do this however, it is important for me to acknowledge that Mr. Falvey's and Mr. O'Leary's approach towards, and interaction with, Sean during the ascent and decent of Carrauntoohil should be described as nothing short of utterly remarkable. Much of this related to their instinctual implementation, through decades of training and experience, of many of the strategies that I only 'discovered' through the course of the fieldwork, such as giving Sean very specific time parameters, granting him control over the situation (he was constantly told he could go back down any time he wanted) and, most importantly, giving him *responsibility on the mountain*- it was Sean's job to monitor our time parameters, and to tell the rest of the team when both it was time to rest and when it was time to get back up and keep going.

Reconsidering risk versus focused ambition

In my interview with Mr. Falvey on the evening of July 28th 2010, completely unable as I was, in the excited aftermath of Sean's extraordinary accomplishment, to divorce myself from the euphoria of the atmosphere within Pat's mountain lodge in Beauford, Killarney (I still genuinely couldn't get my head around the fact that Sean had actually done it), I began my line of questioning, perhaps somewhat over-excitedly, in relation to the sheer element of *risk*. As I was already acutely aware, Mr. Falvey had never underestimated the element of risk in Sean's challenge, but replaying the day back in my mind I couldn't deny to myself that we had pulled off something utterly remarkable that *was dangerous*, which without Pat and Joe's expertise would have been completely foolhardy and, I believe, technically impossible.

"*Look*", Pat explained, attempting to slowly bring me back down to earth, "*it's dangerous, without a shadow of a doubt*". "*Anyone*", he continued, "*who would say that Sean was going*

⁵⁷ There are, in addition, very few photographs of the ascent as Joe, who had agreed to act as photographer, quite rightly felt, in the midst of the challenge that, in the interests of safety, it was more pertinent to concentrate on the task at hand, rather than to focus on photographing the ascent. Nonetheless, what we did manage to capture audio-visually, while balancing filming and photography with safety considerations, still manages to tell an incredible tale of fortitude, resilience, courage and determination displayed by Sean on that day.

to go up Carrauntoohil would have said it was mad because of the dangers involved.... Could something have happened? Of course something could have happened."⁵⁸ But what had finally convinced Mr. Falvey to accept this challenge? This was a challenge that, despite Pat's illustrious career as an internationally renowned high-altitude mountaineer, he had been initially reluctant to accept. The only answer that I can posit is that Mr. Falvey; like Mr. Joe O'Leary, Mr. Corin Morgan Armstrong, Mr. Brendan Cronin and Mr. Gavin Daly, had the courage to set aside his own doubts and chose to see *Sean*- with all of his charm, charisma and determination- first and foremost, and to relegate the 'disabled, autistic Sean' to a secondary afterthought. Faith in personhood, faith in the possibilities inherent within the spheres of human will and human courage, faith in the incalculable potential and power of *human focus* to rise to any challenge with which it is presented when the aim is to help others, and most importantly, faith in the human potential of those who Sacks (1986) describes as "*suffering, afflicted [but] fighting, human subjects*"- to *fight*- to overcome seemingly insurmountable odds is, I suggest, the ideological thread which all of these activity leaders ultimately shared.

As Mr. Falvey so pertinently put it in responding to my line of questioning pertaining to the assessment of risk- "*Was it dangerous?*" he again put it to me in rhetorical fashion, "*of course it was dangerous*". "*But in saying that*", he qualified, "*that's no reason to restrict people from fulfilling their dreams.*" "*I totally and honestly believe*", Pat continued, "*that anyone who has a goal or a dream in life will do anything to actually achieve them. With Sean, if you can stimulate him with goals he'll go out and he'll actually achieve whatever it is he wants to do.*" This is because, Mr. Falvey explained, "*you could see that passion in Sean and that humanity*" which makes impossible feats possible. As I sat in Mr. Falvey's office, at this point almost upon the brink of tears, I was inexplicably moved when Pat said "*for me it was an honour being out with Sean. For everybody who was on that mountain, including the people that we met, it was an amazing experience to see him push his way to what was his Everest*" (Interview- 28/07/2010).

⁵⁸ Nonetheless, Mr. Falvey clarified, "*I met Sean a couple of times and he's a very forthright young fella... Would we have allowed something to happen? We were very, very cautious. In other words when it got into the steep ground we put Sean on a tether, you know that he was held between Joe and myself... of course yes the big fear was going up or coming down but, like you know, that's my profession, I'm a professional mountaineer, and you know, mountaineering is dangerous. But in saying that we have the ability to make it safe- to a degree- but there's no way that anyone could have forecast that everything would have gone according to plan. We had to make it go according to plan.*"

The triumph of the person over the disability

Having gathered myself somewhat together, my second, rather shaky, line of questioning related to Mr. Falvey's perceptions in relation Sean's physical and psychological resilience on the mountain. I had reflected in my post-activity field notes following the climb that *"while Sean did initially have to be very careful and specific in his footing, as his confidence increased so too did the precision and fluency of his footing. Every time he reached a new level on the mountain his physical exhaustion was, almost strangely, paralleled by a physical confidence in his own ability despite the pain and effort he was undergoing. The times when Sean went down were due to exhaustion. While he did lose his balance on occasion he never once lost his footing"* (Post-activity field notes- day 29- 29/07/2010). This, considering what myself and Joe had experienced during our training hike in Gugan Barra, on day 25, I found to be utterly astounding. And in the course of interviewing Mr. Falvey it became apparent that he was actually no less astounded than Joe and I were.

"Today I think I've learned a huge amount about autism", Mr. Falvey remarked. "What amazed me was his ability to retain focus on goals". Sean's goals, Pat elaborated, "were very focused, very clear. His goal was basically to raise money for children in Russia...and when he took that challenge, which amazed me for an autistic child, he took that goal and focused on it. No matter how exhausted he was, he didn't want to disappoint the people that gave the money". "He knew what his goals were", Pat went on. "And when we did actually recommend he go down", he added, "which was just a stimulant to get him going to see what way he'd respond, he responded positively every single time to the fact that I'm getting up, I'm going, I'm going to get there and I'm going to get there on time... and I think you've got some good video footage of that" (Interview- 28/07/2010).

The second (of only 2) dialogue recordings to which Pat referred which appear on 'Sean's Victory' DVD feature him sitting at the top of the 'Devil's Ladder' where, having completed the most technically demanding section of the climb, Sean faced a further 1,000-odd foot gruelling slog to the summit. This was the point at which I said to myself 'enough is enough'. He had accomplished more than any one of us had ever dreamed was possible. It was time to turn back. Yet the piece of dialogue captured on camera was the point at which, I believe, Sean- racked as he was by physical pain- made the *independent decision* to cast off his shackles of self-doubt and pitch himself in the 'final battle'- just like Aron's final battle near

the sun in which he defeated satan- for better or for worse, against the enormity of the challenge confronting him. *"Intense pain is bad"*, Sean said as he sat on the top of the 'Devil's Ladder' fixatedly cleaning his walking stick. *"It is"*, I agreed. *"Do you want to go back down"*, Pat asked. *"No"*, Sean replied. *"You mean- you want to go back down"*, Pat persisted. *"No"*, Sean retorted, *"we have to help the kids....remember!"* *"Come on so"*, I suggested, and with that, up he got, and summoning reserve strength from some place that I will never know, headed off towards the summit of Carrauntoohil.

As my interview with Mr. Falvey neared its conclusion, I asked him to finally comment upon how he felt Sean responded to structure and authority, as well as upon the vital issue in relation to Sean's regulation of time. *"He actually addresses authority very well"*, Mr. Falvey responded. *"He addresses the fact that if it's the case that you know, he was told it was dangerous, he was told he needed to do as he was told. He was told in no uncertain terms"*, Pat reflected, *"that there was a hierarchy of structure in relation to his instructions."* *"And he took them"*, Pat went on, *"and he took them very seriously. Did I actually set objectives?"*, Pat put it to me. *"Of course I did"* he said. *"But did Sean understand them, which was more to the point?"*, Pat again put it to me. *"He did"*, Pat concluded, *"he understood he had to be at the summit for three o'clock. If he was ten minutes away from the summit by then he was assured we were going to have to turn. So all the time he was looking at the watch, he was processing the time that he had to do it. He was completely, utterly focused on achieving his goals within the times that were set for him. When we said sit down we gave him the responsibility of saying let's go, he watched the watch and he said 'let's go'. When it came like to six minutes past two and I said it was six minutes past two he looked at the watch, and the minute the watch hit six minutes past two he said 'get up'"* (Interview- 28/07/2010).

Sean Cronin- an Irish hero

After our interview had ended, and I had switched off the Dictaphone, Pat turned to me and said *"Steve, I hope Sean has got something out of today and that he'll hold it."* Pat was echoing a sentiment that he shared with myself and Joe, namely that Sean would internalise a sense of pride and achievement as a consequence of his accomplishment, that in the words of Mr. Corin Morgan Armstrong, the experience could potentially serve as a 'catalyst for change' for Sean. And this was a very significant point. The difficulty is that Sean does not seem to possess anything even moderately resembling an ego. As I recorded in my post-

activity field notes, *“it is astonishing to consider that despite the enormity of his achievement, Sean was extremely reluctant to take any praise or credit for it. He was completely focused on the fate of the poor children of Russia- ie the outcome- they would now get the money- but he would not allow himself to internalise any pride for his achievement”* (Post-activity field notes- day 29- 29/07/2010). As I will discuss in my concluding discussion, it was ultimately the *dissemination of data-* its post-fieldwork application- that allowed this to happen.

I would like to conclude this chapter by quoting the speech, in abridged format, made by my father, Joe O’Leary, on the occasion of Sean’s awards ceremony on the evening of December 14th 2010. I believe that Mr. O’Leary’s inspirational and heartfelt words speak entirely for themselves.

“I’ve been a mountaineer for over 30 years and I would have taken hundreds of people up Carrauntoohil. But this was special. Because of all the people I’ve taken up there I’ve come across very few people who have had the courage and the strength that Sean portrayed on that day. Now, Sean found it extremely difficult. And there are times that I’m sure that he’d have liked to turn back. And we asked him as well, Sean do you want to turn back, but no, the commitment was the children of Russia...When you go on a marathon and you hit a wall at, you know 20 miles or whatever, well Sean hit 5 or 6 walls on that day but still got up and kept going. And, to be honest about it, I didn’t think he’d make it... But that was my mistake. I totally underestimated Sean. And we eventually got to the top of the mountain. And I can feel it here tonight too. There was a feeling of elation. There was a warmth.

As you know, Sean is a great fan of Westlife and, taking the words of the song ‘you raise me up so I could stand on mountains’, well, Sean actually raised us up on that day because Sean made us feel special that day. All I can say to you, Sean, I think Sean was a true inspiration to us all on that day because he taught me two things. The first one is that you can never prejudge anybody. I didn’t think Sean would make it, and I was wrong. And also he showed us that with strength, commitment and, I suppose help from others, you can really achieve anything. So what I have to say to you Sean is- thanks for a wonderful day.”

CHAPTER 5- DISCUSSION, CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Approaches towards teaching children and young people with autism

Traditional approaches towards teaching children with autism

In the introduction to this thesis I explained that my dealings with Sean were initially located within an ASD unit attached to a mainstream school, a unit which I was set the challenge of piloting and coordinating in September 2008. I went on to explain that I abandoned an idea of presenting a ‘model of best practice’, a ‘template’, if you like for other schools to potentially emulate for a number of reasons. Foremost amongst these was that the programme that I had developed had been essentially a ‘junior programme’ and had not yet fully explored issues relating to transition from school to society and long-term adult outcomes for the young people enrolled in the programme.

In response to this, the case study presented in the previous chapter was essentially an attempt to explore the issue of ‘quality of life’ for one of those pupils- Sean- which, as I stated in chapter 1, I hoped may bring about findings- or at least insights- that may be of some relevance to teachers and parents of young people with autism, as well as perhaps to those young people themselves. Thus the findings presented in the following chapter are not directed specifically towards any one set of ‘stakeholders’, but are rather intended to be accessible to any person whose life has been touched by autism. However, it is important to initially relocate this chapter within the established models and approaches that have traditionally underpinned the education of children and young people with autism (as described in chapter 2) for reasons that will become apparent throughout the course of this chapter.

In my critique of the TEACCH, ABA and ‘Son Rise’ approaches towards teaching children with autism presented in chapter 2, I suggested that these may be reduced to 2 fundamental points of contention: whether to attempt to ‘normalise’ the child’s behaviour to the greatest extent possible through means such ‘schedules of reinforcement’ and ‘structured teaching’, or whether to ‘join’ the child in his/her world and by addressing issues such as judgement, motivation and control, attempt to guide the child towards the social world. As chapter 2

explained, the modern practice of ABA was born out of the work of Dr. Ivar Lovaas at the University of Los Angeles, who succeeded in reducing the self-injurious behaviours of autistic children through his system of ‘discrete trial training’. Similarly, in my many conversations with Sean’s parents and former ABA tutors it became clear that ABA played a vital role in helping Sean to master the basic skills to allow him to live a functional life. Indeed, both the empirical and expert strands of the Parsons *et al* (2011: 58) study found evidence which highlighted “*the importance of early intervention, in particular, interventions that focused on early communicative behaviours*” for children with autism.

In addition, chapter 2 noted that TEACCH is essentially based upon creating working and living environments that may be termed ‘autism friendly’. Creating a predictable sense of order in such environments may be crucial for many people with autism, be they children, young people or adults. In developing the physical structure of the Nagle CC ASD unit a key consideration was the scope of the physical environment to help the pupils to organise themselves; thus the development of highly structured spaces for the display of individualised timetables (sometimes visual, sometimes written depending upon the needs of the person), separate spaces for the storage and accessible retrieval of individual pupils’ belongings, as well as the allocation of identifiable spaces for activities such as occupational therapy, sensory activities, ‘chat time’, ‘circle time’, musical activities, IT etc. Perhaps the only difference between the physical design of the unit and that of a typical TEACCH classroom was that all ‘workstations’ were cooperative (i.e. there were no individual workstations). Similarly, I have seen how PECS can serve as an invaluable tool, in both home and school environments, in helping a person with autism to express his/her functional needs. This chapter does not argue that functional communication should be ignored, but rather that functional communication is only *one* form of communication and that alternative vehicles for communication- which take account of *self-expression*- are equally important to be aware of when working with individuals with autism.

Essentially, this study concedes that different forms of provision may have their appropriate time and place in a person’s life. As Sean’s father put it, “*there came a point when ABA had run its course, and the stats themselves pointed that out*” (Post-fieldwork interview, 03/09/2011). Sean’s resistance to behaviourally-based instruction in the latter stages of his ABA education was not the ‘fault’ of ABA as a methodology, but was rather an indication that ABA had served its purpose, ‘done its job’, and that it was time for Sean to move on to

something new. A key point to be made, as ASD-specific methods relate to this study, is that approaches towards creating structured and predictable home-based and school-based environments have little or no relevance to the unpredictability of the social world. As I stated in chapter 1, what attracted me to the approach undertaken in this study lay in its inherent challenge to take a much wider view of education; education that extended beyond the perimeters of the school walls. The ‘gap’ in the literature that this study attempts to address relates not to a school-based interventionist approach, but rather to the call made by Parsons *et al* (2011: 61) for “*research on educational settings to address explicitly questions of social validity and longer-term outcomes for children, young people and their families.*”

Challenges and opportunities for ‘ASD units’

Many of the arguments and suggestions put forward throughout the course of this concluding chapter may, I suggest, have high degree of relevance to those embarking upon the development of new ASD units in the Cork area. This chapter is structured around 4 key cornerstones. These are 1) the importance of developing democratic relationships with parents of young people with autism based upon a *reciprocal* approach towards communication, 2) developing multi-faceted approaches to communication when working with individuals with autism, 3) facilitating young people with autism in forming meaningful, enduring friendships with others, and 4) the importance of factoring in the concepts of choice, control, challenge and celebration in the enrichment of the lives of young people with autism. These areas of discussion are not random but are in fact framed in response to some key concerns of parents of young people with autism that were highlighted in the Wittemeyer *et al* (2011) study which has been referenced throughout the course of this thesis. *While the Wittemeyer et al (2011) study was not published until the literature review was completed, it has since become a crucial publication in which the findings of this revised thesis have been considered.* There are currently no published guidelines available to schools as to what purposes ASD units should serve for young people with autism in Ireland despite there being a virtual ‘explosion’ in the development of such units and special classes since September 2011. In light of this absence, it is worth drawing attention to the views and concerns expressed by the parents of young people with autism- as to their most desired educational outcomes for their children- that were gathered in the course of the Wittemeyer *et al* (2011) study.

The authors of the study identified some key concerns expressed by parents of young people with autism in relation to what their most desired educational outcomes were for their children. These may be summarised as follows (Wittemeyer *et al*, 2011: 28-44):

:

- Parents placed the importance of their child's ability to cope socially and form social relationships, to 'enjoying being with other people' in adult life, far above academic attainment and expressed a wish that programmes targeting the former would take precedence over the latter.
- Parents expressed a wish that the development of their children's strengths would take precedence over the remediation of their deficits in educational planning and practice.
- Parents further expressed a wish that their other children would be given help and support in learning how to help their autistic sibling.
- Education was a short-term priority for parents. Parents expressed a wish that their children's educational programme would take account of long-term employment options, and allow their children 'reach their full potential' when they became adults. Those desired employment options were not limited to functional employment options, or even necessarily paid work, but rather emphasised the importance of 'meaning and purposeful activities in adult life' including leisure activities.
- Emotional well-being, self-esteem, self-confidence and happiness were reported as being among the most important short-term factors in determining the merits of their children's educational placement.

Parsons *et al*, (2009) presented a figure of 170 children and young people attending autism-specific classes/units in the Irish republic in 2009. It is likely that this figure has increased dramatically since then (although there are currently no available figures indicating what this number may now be). On March 16th 2011, I was invited to make a presentation to representatives from 20 post-primary schools in the Cork city and county areas that were considering the development of ASD units in their schools (the prospectus for the 'Facing the Challenge' seminar is included in appendix N). At that time there were only 2 post-primary ASD units (with a combined total of 30 places) serving Cork city and county. Following the seminar, of those schools represented at the event 5 opened ASD units in September 2011, while at least a further 10 are due to open ASD units in September 2012.

This study contends that the growth of unit-based provision in Irish post-primary schools represents an exciting *new opportunity* for special education provision in Ireland to explore new concepts of education that may be responsive to views such as those expressed by the parents consulted in the aforementioned Wittemeyer *et al* (2011) study. However, it is important to likewise identify some practical, logistical and even moral challenges that the developers of ASD units will likely be forced to contend with in responding to parental wishes, such as those expressed in the aforementioned study. These challenges may be said to relate to 1) the lack of consensus as to the *purpose* of ASD units, 2) the ingrained barriers mitigating against the inclusion of young people with ‘low-functioning autism’ in semi-integration programmes in mainstream settings, and 3) the lack of an evidence base to refer to or draw upon.

In relation to the first challenge outlined above, it should be stated that there has been no attempt to define what ASD units/special classes *are actually supposed to be* and *what functions they are intended to perform*. Neither has the ‘inclusion debate’ explored the inherent *opportunities* that exist for unit-based centres of provision to address the aspirations that parents of young people with autism have for their children, as well the aspirations of those young people themselves. Parsons *et al* (2009) reported a notable lack of qualitative data relating to the *experiences* of older children and adolescents with autism across the spectrum of educational provision in Ireland while, as previously mentioned, Wittemeyer *et al* (2011) raised the issue that educational provision for young people with autism rarely matches the aspirations they hold for their own lives. As Parsons & Guldborg (2011: 59) put it, “*given the significant debate that exists in Ireland and the UK (and beyond) regarding inclusive education and where it takes place, there was a surprising lack of independent research as to how autism-specific classes (in either mainstream or specialist settings) operate and their influence on individual outcomes.*”

Involving parents as co-assessors of their children’s education

A key difficulty underpinning this dilemma relates to how ‘progress’ is gauged within autism-specific teaching programmes at post-primary level. Despite a ‘unit’/‘special class’ assuming certain, different aspects of identity from the host school in question, how ‘progress’ in such a unit or special class is measured is still carried out within the context of the state examinations. As Parsons & Guldborg (2011: 59) again put it “*currently, there is a*

strong emphasis on academic attainment as a measure of a school's effectiveness, yet many in the field of autism feel that other goals are equally important. These include communicative competence; social understanding; physical and emotional well-being; and independence skills."

This has very serious implications for those embarking upon the development of ASD units at post-primary level in the Cork area. A challenge for those developing new approaches towards teaching young people with autism, this study contends, lies in opening up channels of communication with parents that invites them to become joint collaborators and assessors in their child's education, beyond a 'subject centred' system of assessment that may have little or no relevance to the young person in question. This would involve, as Crozier (2000) 125) puts it, the development of parent-teacher relationships based upon "*participatory democracy and respect...parents trusting teachers and teachers trusting parents.*" As I alluded to in chapter 2, the TEACCH approach towards teaching children with autism places a high degree of emphasis upon the role of parents in informing the direction of their children's education. The parents interviewed in the Wittemeyer *et al* (2011) study reported that staff in special school settings were far more open to their views and opinions- displaying more of a 'genuine reciprocity'- than staff in mainstream schools.

Vincent (2002: *xii*) makes the point that in mainstream schools "*the opportunity for parents and teachers to engage in a debate concerning children's welfare and educational progress...has been marginalized.*" Yet, as discussed in chapter 2, the role of Sean's parents as co-researchers- as active participants in the project- was crucial to the project's development and its eventual outcomes. This study contends that parents are experts on their own children and that they should be respected as such. According to Turnbull *et al* (2000) the role of an individual's parents, siblings, family and close friends in 'person centred planning' is generally acknowledged as being hugely significant for the planning process. This study acknowledges the incalculable power of parental involvement in the assessment process, adhering to Sanderson's (1998: 135-136) view that "*assessment should be an ongoing process of discussion and observation rather than measuring people against set criteria*", and should incorporate "*a shared style of assessment, namely an 'exchange model of assessment', where professionals move from being the 'experts on the person' to being experts in the process of problem solving with others.*"

The rather drastic implication of involving parents as co-assessors in their children's education, yet an important one nonetheless, is that such an approach towards assessment *shifts the focus of assessment* towards the efficacy of the *delivery of educational provision itself*, as opposed to focusing exclusively upon the assessment of the young people themselves. Whilst as stated in chapter 1, young people may be said to constitute the fundamental 'units of analysis' in education, the 'focus of analysis', this study contends, should be pointed towards the nature of educational provision itself.

A 'community-based' approach towards education

Despite there being virtually no 'outcomes research' for young people with autism in specialist forms of educational provision in Ireland, if we are to return to the views expressed by those parents interviewed in the aforementioned Wittemeyer *et al* (2011) study, the overarching consensus seems to be that autism-specific models of provision should focus upon long-term outcomes relating to quality of life for young people with autism over short-term academic attainment. This has further serious and significant implications for those embarking upon developing ASD units in the Cork area.

The views of those parents imply that 'inclusion', conceptually speaking, needs to be extended *beyond* that of a 'within school' phenomenon, to that of a 'community based' phenomenon. The implication of this is that educational practice should be extended into the community itself. If the aim of special education, as stated in the EPSEN Act (2004) is indeed to "*assist children with SEN to leave school with the skills necessary to participate to the level of their capacity, in an inclusive way in the social and economic activities of society*" (section 1), then it *simply makes sense*, to the greatest extent possible, to locate pedagogical practice *within the community itself*, and to consequently apply the concept of inclusion to the wider school community. This would imply educational provision taking account of *context*, a principle underpinning the UNESCO Salamanca Statement (1994) which maintains that the origins of children's learning difficulties lie not just in themselves but also in the environments/contexts within which they are required to learn.

The aim of an 'ASD unit' for young people with autism should, this study contends, be to help them to become *active citizens* within their local communities, whilst identifying either short-term or long-term supports that may be required to be put in place in order to support

the transition from school to life. As Sanderson (1998: 132-133) puts it, “*rather than independence, it is interdependence that we need to focus on...instead of asking ‘what skills do we need to teach next’, the question is ‘what would it take to support this person to be part of their local community?’*” Such a vision suggests an engagement with the concept of citizenship, a concept which Lawson (2010) argues provides contexts in which all pupils, particularly those with learning difficulties, may move away from a personal view of themselves and their immediate world, towards a much wider perspective that helps them to think about other people, and ways in which they can make a difference to others and the world around them. Within the educational system, Lawson (2003) argues, pupils should be encouraged and facilitated in being active participants, as ‘meaning makers’, as ‘citizens now’, rather than in the future, by living and experiencing participation in the community.

During a recent visit to Sean’s home I asked him what was next on his ‘agenda’. His response was that he wanted to now help “*those good people of Africa*” after which he would return to helping “*the good people of Russia.*” This has important implications in conceptualizing what ‘employment’ may mean for different people and the role that having a job- a *purpose*- may have in an autistic person’s life. Factoring in the views of the parents of young people with autism, as well as those people themselves in relation to their aspirations for their own lives may, as Temple Grandin puts it, lead to “*jobs that would be careers instead of just jobs*” (Grandin & Duffy, 2004: 78). Wittemeyer *et al* (2011) stress that in all cases of educational planning for good adult outcomes, the opinions of the young person with autism should be central in guiding the process. Furthermore the authors reported that all of the children interviewed in their study stated that they would like to have a job which usually revolved around their talents or interests. Helping young people with autism to cultivate their strengths, in the words of Temple Grandin, means “*observing and listening and an awful lot of reflection.*” “*Allow your children to spend time developing their fixations into hobbies*”, Grandin advises, “*notice his or her interests and passions- even if they seem a little off the wall or different*” (Grandin & Duffy, 2004: 53).

Access to education for young people with autism

Due to the fact that ‘progress’ within ASD units/special classes is ultimately measured in terms of pupils’ attainments within the state examinations (Junior Certificate in year 3, and Leaving Certificate in year 6), it is perhaps inevitable that access to semi-integration

programmes has been largely limited to those who are deemed to be more ‘academically able’. Removing this restriction, with a view towards exploring new concepts of possibility in the education of young people with autism, is perhaps the greatest challenge that those setting out to develop new ASD units will inevitably face. As Carey (2009: 1) puts it, “*if it wasn’t enough that ASD educational provision is slipshod for the most part and downright non-existent in most secondary schools [in Ireland], upon agreeing to open a special class the school will begin the admission process which typically specifies that no child on the spectrum who has intellectual impairment (sub-average IQ) will be enrolled in the class. This clause means that up to 85% of adolescents on the spectrum will be denied admission to a unit which purports to specialise in their education.*”

Management figures within schools often take the view that pupils with autism who apply for enrolment into ASD units should be prioritised based upon the number of mainstream subjects that they judge they could realistically attend. And this, fundamentally- in my view- acts as the *single greatest barrier* to achieving meaningful ‘inclusion’ for young people with autism in centres of unit-based provision. The question should not be to what degree a pupil with autism can attain academically in mainstream subjects. ‘Inclusion’- conceptually speaking- should not be approached quantitatively. This study contends that it is not necessarily true to suggest that the more subjects a pupil takes in the mainstream section of a school positively correlates with the level or depth of ‘inclusion’ or wider opportunity that is afforded to such a pupil. And schools, in my view, should not be deemed to be more or less inclusive in terms of such criteria. The question *should be*, and the criteria upon which schools *should be* judged in terms of their ‘inclusively’, is the degree to which they are prepared to include those apparently beyond inclusion, in new imaginative ways that regards neither the ‘special class’/‘unit’ or mainstream classes as constituting the only contexts- ‘sites of experience’- in which learning can take place.

In ‘Facing the Challenge’ (O’Leary, 2011) I *asked* school managers to suspend deficit assumptions in relation to what ‘low-functioning’ pupils with autism may achieve, academically or otherwise, and to rather consider what an enormous contribution such pupils may potentially make to school life. In this case study I have attempted to *show* them- if only through one example- what it is possible to accomplish when those judgements are suspended. In presenting this study I have attempted to tell a story wherein it may become naturally obvious to the reader, in the course of experiencing the story, that people with

autism are neither ‘high functioning’ nor ‘low functioning’, but rather that *they ‘function’ at the level to which we permit them to function*. This study hopes to have illustrated- if only through one example- *one story- Sean’s story-* how when pessimistic presumption is cast aside in favour of faith and optimism, when the notion of possibility is held in higher esteem than that of the probability of failure, when we dare to challenge the impossible *by imagining the possible*, then achievement is within the grasp of any motivated person.

This thesis is presented as evidence of what a person diagnosed as having autism in the ‘severe range’ (see appendix A) *can achieve and contribute to the school and the community as a whole* when a person’s ‘human condition’ is elevated above his/her ‘autistic condition’. The presentation of Sean’s cheque to ‘Chernobyl Children International’ on the occasion of his award’s night, as well as the subsequent letter of thanks that he received from its CEO (see appendix O) demonstrated his enormous power to become a ‘meaning maker’ in his community and to act as an ambassador for his school. The ‘Awards Night’ event (14/12/2010) powerfully portrayed inclusion as a community-based phenomenon, transcending ‘disability baggage’ and demonstrated that not only can people with autism be ‘included’ in school and society, but can assume the role of leaders and ambassadors when given a community role. Sean’s ongoing involvement with the ‘Chernobyl Children International’ charity as an outcome of this study, for instance, is a powerful indicator of the potential of people to become active and respected members of their communities when the concepts of ‘school’ and ‘community’ are brought closer together. It is hoped that this study may encourage decision makers and managers in education, if only on a local level, to question- *for themselves-* some of the entrenched stereotypes in relation to autism *as a condition*, and in light of this, to open their doors to young people with more severe forms of autism who may no longer be acquiring any real benefit from what special education placements can offer them in addressing their adult aspirations for their lives.

‘Communicating’ with young people with autism

This study argues that human *connection* is the fundamental prerequisite to human communication and that meaningful communication can take much deeper forms than speech when the phenomenon is explored in a number of forms across a number of contexts. Just because certain people with autism ‘can speak’, and are consequently expected to communicate through speech, this does not necessarily mean that when they are speaking

they are truly expressing themselves. Finding a way to connect with people with autism when speech is impaired may, this study suggests, be achieved through an engagement with the concept of 'narrative' on a number of levels.

Connection through the 'internal narrative'

Narrative, this study contends, may provide a 'bridge', a 'tapestry', or a 'common ground' across which the 'world of autism' may be connected to the world that surrounds it. In the early years, during the period of the 'Aron Narratives', despite the fact that Sean is 'verbal', he would rarely speak to me. Yet he would spend hours drawing for me and over the course of time, he developed the trust to allow me watch what he was doing. To teach a person with autism, this study contends, one needs to first learn about them. The 'teacher' must become 'learner'. Understanding how a person operates in the world of narrative may, in the initial stages, only be reached through a period of observation. The pupil may, for instance, be invited to simply draw what is going on in his/her mind- the internal narrative- in whichever form it exists. That is how I met Aron, and it was through Aron that I first really 'met' Sean. Wendy Lawson, Donna Williams and Temple Grandin all write of the importance of learning to read their 'inner narratives'. "*As I grew older, I learnt to listen to the talk in my head*", Wendy Lawson (1998: 138) tells us. Donna Williams adds that only by learning to read her own inner narrative did she become fully aware of who *she* was- *in relation to the characters she herself had created*. "*A self must have a past*", Williams (1994: 13) tells us, "*Willie, Carol and Donna each became aware of who they were in relation to one another.*" Temple Grandin urges the educators of people with autism to help them to "*write about what they are noticing...both the outside world and the inner world*" (Grandin & Duffy, 2004: 58). Yet to do this takes time. In the case of Sean, a *connection*, based upon trust, had to come before he would permit me access to his inner world.

Yet, surely enough, after months of simply 'being with' Sean, just sitting with him as he created his hundreds of disconnected drawings and dialogues, a verbal explanation did eventually come, albeit entirely unexpectedly. "*Aron*", Sean explained to me, "*is really Jesus...a famous protector of earth. God took him to a house. The time that this happened was between the 21st and 22nd centuries. He was adopted as a baby and was raised by his mother, father, little sister and little brother. The main bad guy of the game was the Devil-Satan. Aron got the name from a friend who was a nice guy. He becomes half human, half*

dragon and goes through different universes. When Aron stops the attack he falls down. His spirit was transferred to the spirit world. Those universes [pointing at figure A- see appendix G] became real universes. He became friends with the good guys, well some of them...Aron's in love with the Devil's Daughter. Her name is Ciara. There is an evil version and a good version but she's always good ol' Ciara. Her true father is God. Hell is the final location in the final battle. Hell is the Devil's home. The Devil's Daughter becomes good after the battle. She turns into a beautiful women. Heaven has flowers, trees and nice animals. It becomes headquarters after Aron meets Jesus. Aron's hair is black. Was Jesus' hair really black?"
(See appendix G)

In that moment Sean became an expert on autism, an expert upon his own human condition, an expert commentator upon his own life. He became *my* teacher and in the process afforded me unique glimpses and insights into the world that I was so intent upon exploring: the fascinating and intriguing 'world of autism', a world of the most skilful adaptation, of imagination, of love and of empathy; a world of survival, a world of mastery, of genius-insular genius perhaps- but genius nonetheless. This study found that not only does Sean deeply engage in narratives on a 'cognitive' level, but that he also engages in certain narratives- both internal and external- on a profoundly emotional level. While Sean's case- as it relates to the internalisation, processing, and communication of narratives- may be said to be somewhat extreme⁵⁹, I do believe that this study may illuminate some aspects of narrative processing that I believe are important to consider in applying the concept of narrative to that of autism. This study found that Sean himself may feel personally complicit within the hybrid narratives that he himself creates in his mind by drawing together characters, locations and action sequences from a multiplicity of narratives taking different forms. His extreme upset that he "*made those bad things happen*" when "*New York was invaded by monsters, big green trolls*" in the 'Alex Raven' narratives, a protagonist- who like Aron who preceded him- seemed to be involved in an exploration of the dichotomy of human nature (which will be explained shortly), suggests to me that individuals with autism may apply an *intensity of focus* to their preferred forms of narrative that may be just as real- if not *more real*- than 'real life' itself. Narrative, for Sean (like Donna Williams), became infinite. It became 'life'. And

⁵⁹ How Sean uses his hands as a means of internal communication with himself, and how this may be extended to communication with others would make a fascinating follow-up study in my view. There are many connections between the hand and language. At the neurophysiological level there are similarities between the skills required for speech production and those required for hand movement, specifically movement of the right hand (McGilchrist, 2011).

thus it fell to him to influence its course, in particular to find ‘endpoints’- happy endings- in a search for meaning and justice in a virtual world.

And who could blame Sean- or indeed any other person with autism- for lending more importance to their own worlds of individual interest, to the point of crossing the boundary of what separates reality from fantasy, when the *alternative- the social world-* is so often dull, scripted and devoid of imagination. And the greatest irony of all is that the condition of autism is described as one in which the *person themselves* is entirely dependent upon scripted, predictable routines and is entirely devoid of imagination. People with autism are no more devoid of imagination than they are of empathy. In fact, this study suggests that such individuals may be said to possess powers of imagination, flexibility and creativity that people who do not have autism fail to understand for the reason that *they simply just don't know what it's like to have autism.*

Communication through the ‘external narrative’

Similarly, during the course of the fieldwork activities Sean and I shared together, shared *external* narratives- narratives that both of us could relate to and understand- such as ‘Father Ted’, allowed Sean to both generate and maintain conversation with me on a day-to-day basis and, just as importantly, allowed me to reciprocate his interests in conversation. For instance, the much aforementioned day (day 21) in O’Brien’s coffee shop was punctuated, as Sean dipped in and out of his ‘Simpson’s’ comic, by a mutually held appreciation of hilarity of the occasion when *“Ted jumped through the window.”*

Perhaps, on one level, the scope for narratives to serve a communicative purpose for individuals with autism may be said to reside in their scope to bring together and amalgamate the visual and phonographic aspects of human memory. As alluded to throughout chapter 4, much of Sean’s ‘language acquisition’ might be termed ‘scripted language’: chunks of language that are directly copied from movies, TV shows and so forth. This is in keeping with Donna Williams’ account of her own acquisition of language in which she testifies that *“with language echoed from storybook records, TV commercials, and stored conversations, Carol could buy my way through life, albeit recklessly and obliviously”* (Williams, 1994: 12). Yet perhaps the more inherent power of narratives to *connect*, to facilitate ‘joint attention’, may be said to reside in their scope to allow a person to express and project, or perhaps

simply appreciate, something of themselves without having to explain (or even fully understand) exactly what they mean or claim to represent. Narratives respond to the uniquely human impulse and human instinct to tell stories, and to communicate through story. Narratives are *representational* texts: the messages embodied within them are more subliminal than explicit and thus invite interpretation rather than explanation. Most importantly, narratives allow for common interests, common emotions, a common ‘sense of humour’, and common points of view (as well as differing points of view) to connect across a shared tapestry. This study found that times when a ‘remarkable fluency’ came into Sean’s speech did so upon occasions when he was after sharing a stimulating narrative experience with another person/people, such as after the Granary Theatre performance (18/06/2010) and the ‘Westlife’ performance (07/07/2010).

Communication and friendship

Motivation for friendship

In the aforementioned Wittemeyer *et al* (2011: 27) study it was found that “*children [with autism] generally expressed a strong desire to have friends, although difficulties establishing and maintaining their friendships was apparent in several discussions with young people*”. The study further reported that the parents’ of young people with autism “*top priority for their adult offspring in both the short term and the long term was to build social relationships.*” (ibid: 29). The question then becomes one of how we may help and encourage young people with autism to develop and maintain friendships with others.

Where does friendship begin for people with autism? For some, this study suggests, it may begin internally. “*People were forever saying that I had no friends*”, Donna Williams (1992: 14) tells us, “*but in fact my world was full of them. They were far more magical, reliable, predictable, and real than other children, and they came with guarantees.*” In chapter 3, I posed the question as to what function Sean’s invented characters actually served. Whilst they served multiple purposes, that are referred to throughout the course of this chapter, for him- on a basic level- they may be said to have constituted an internal network of virtual friendships, ‘friendships’ that were easier to control, as well as being more ‘honest’ and predictable, than the confusing world of human relationships.

People who live behind a ‘world of glass’, as Wendy Lawson described it in chapter 2, and who may speak very little (if at all) do not lack the *motivation* for friendship; the motivation to *connect*. As chapter 2 explained, the ‘urge’ to communicate is not a linguistic phenomenon associated with the Brocca’s Area or the posterior superior temporal gyrus (Wernicke’s Area) of the more ‘evolved’ left hemisphere, but rather resides within the deeper, ancient subcortical structures of the limbic system. The construction of a virtual autistic world, this study contends, does not constitute a rejection of friendship but is rather a brilliant accommodation in finding ‘points of connection’ in an internal world when the external world is too difficult to reach.

Acceptance in communication

Despite living almost exclusively within his internal world prior to the study, this study showed how within a relatively very short period of time Sean could develop new ‘external’ friendships, referred to in chapter 4 as his ‘web of personal linkages’. Yet only *complete acceptance in communication*- this study found- was the key to making this happen. On the most fundamental of levels such acceptance was crucial in allowing Sean to maintain his newly emerging web of friendships in memory. The ‘undiluted directness’ that Sean often displayed in a variety of contexts throughout the course of the study was not, as chapter 4 discussed, an attempt to be deliberately rude or hurtful; his questions were rather attempts to ‘locate’ and retain new people in his memory. Locating or ‘encoding’ key project participants in memory was for Sean achievable only by 1) finding out key details about them (such as their family connections), 2) through *stories* about them, and 3) by discovering a person’s ‘function’. For Sean, the stronger the person’s ‘function’ the easier the person was to encode and retain in memory: hence his fascination with famous people who have very identifiable functions.

During the course of the study, once a person had been ‘encoded’ or ‘located’ in Sean’s memory through direct questioning (however seemingly ‘inappropriate’ at times), and after which he was consequently able to ascribe them a specific function or ‘identifiable purpose’, it was then possible for him to link them to one another. So for instance, I myself- “*the son of a famous mountain climber*”- was linked to Joe, the “*famous mountain climber*”, who was then linked to Pat Falvey- another “*famous mountain climber*.” I was also linked to the “*famous actor*”, Cillian Murphy through my schooldays, who was further linked to his

parents Brendan and Mary Murphy- "the parents of a famous actor." Brendan and Mary were then further linked to Joe (and I) through teaching in a former school together; and so the web developed. As Sean's personal writing extract on the following page illustrates, the web kept widening beyond the course of the fieldwork to include 2 more of my "famous friends" from my school days- rugby players Peter Stringer and Ronan O'Gara, who despite Sean having no interest in rugby whatsoever, became deeply interesting to him since they could be further linked back to Joe (who is friends with Ronan O'Gara's parents), Brendan and Mary Murphy (who are also friends with Ronan's parents), and I (who have a cousin who is Peter Stringer's partner).

Personal extract writing A- 'A great achievement'

Section 2. A Great Achievement.

I go to school in Nagle Community College. Steve O'Leary is my Teacher and my Friend. He has 5 famous friends including his father whose name is Joe O'Leary. Steve's famous friends are Cillian Murphy, Ronan O'Gara, Pat Falvey and Peter Stringer.

Pat Falvey is a Famous mountain climber. I wanted to ~~make~~ help the poor kids in the orphanage in Russia. Steve rang Pat and ask him if I can climb Carruntoohill to raise money for the kids I had train with Joe O'Leary. He is a nice man.

The day I climbed Carruntoohill it was painfull. It took about 6 hours to finish the climb.

The point to be made is that in the early phases of developing a ‘web of personal linkages’, remembering people (which Sean had always found very difficult, often completely forgetting people he had previously met) was achieved through *association*, the biochemical process as described by Gibb (2007) in which- while we sleep- the neurotransmitter CREB creates new synaptic connections between partnering neurons, bringing about new networks of strengthened neuronal connections. Yet the ‘maintenance of the web’ cannot be explained solely mechanically or neurologically. The people who were maintained in Sean’s ‘web of friendships’ were people who had treated Sean with unfaltering respect and dignity, as described throughout chapter 4. Incidentally, the people in ‘the web’ who Sean never met were people who Sean was told heard of Sean and his charity work (which they did), and sent their congratulations to him- something that had a remarkably powerful effect upon him.

Revisiting acceptance and rejection

Acceptance or non-acceptance/disapproval is something that people with autism can ‘read’ just as well (and are perhaps even more finely attuned to reading) as non-autistic people. Whilst it may be true that people with autism experience difficulty in reading the emotional shifts of the face- minute facial changes which, as McGilchrist (2009) tells, us are normally processed by the right hemisphere in 300-400 milliseconds, at levels beneath conscious awareness, people with autism may be highly attuned to reading people’s responses to them in other ways such as, for instance, intonation of the voice, and the responses they receive to what some may regard as ‘inappropriate’ questions or behaviours. Like the children and young people interviewed in the Wittemeyer *et al* (2011) study, Sean (although not being aware of having ‘autism’) was likewise, this study found, deeply conscious of having ‘something’ wrong with him. As I described in chapter 4 his initial dislike of being filmed whilst ‘pretending’ because, in his own words; “*people will think I’m crazy*”- spoke of a young man who, like almost all teenagers, did not want to be seen as ‘different’.

That in my view, acted as the single greatest barrier to Sean developing friendships prior to the study. In the introduction to chapter 4, I described that prior to the study Sean went through weeks and months in which he barely, if ever, spoke throughout the course of a school day, entirely engrossed in his world of pretence. In retrospect it is likely that, like Donna Williams, he had slipped further behind a ‘world of glass’ because he assumed that his ‘pretending’ was something to be ashamed of. Those who in the course of the study

developed close bonds with Sean were those who never cast judgement upon his apparently ‘unusual’ behaviour. He was always free to ‘slip in and out’ of his own inner world as he wished. Yet paradoxically, when that freedom and choice- to simply be ‘himself’- was in place; when judgement was completely ‘shelved’ for 2 months, he spent less and less time in his own world of pretence and when he did ‘slip in and out’ he did so in such a way as to invite the other *into ‘his’ world*; in the process revealing the meaning and significance of that world to him. In so doing, he was *connecting* with others, developing *trust* in others, and developing an ever increasing interest in *their* world.

Friendship and the ‘child-adult’ issue

This mutual interest was made possible only by treating Sean as an *adult* individual, as opposed to a ‘child with autism’. As the study revealed, while Sean can relate very well to young children on a ‘childlike level’, he does not see himself as a child and does not like to be seen or treated as a child. Further times when a ‘remarkable fluency’ came into Sean’s speech were those times when he was engaged in stimulating adult-orientated activities, such as when yachting (14/06/2010), when he was preparing to take on a challenging activity to help others, such as during the drive into the foothills of Carrauntoohil (28/07/2010), as well as when he was engaged in adult conversations relating to his interests, such as during the journey to his Tae-Kwon-Do session (23/07/2010). The key thread tying each of these exemplars of sustained, excited verbal communication together was that in each of these instances, not only was Sean motivated, but he was in the process of forming powerful *adult connections* which fostered a *drive to communicate* which, in turn, often revealed the hidden depths of his knowledge and interests across a number of adult-orientated topics.

As I put it in chapter 4, the point is not to deny the ‘child’ in Sean, but equally, to respect the adult in him. The same might be said for countless young people with autism, who whilst often retaining ‘childlike’ interests such as cartoons and comics right into their late teens, may have other equally important, yet unexplored, adult interests and aspirations for their lives. However, an assumption that people with autism have an “*across the board functioning level*”, as Jim Sinclair (2011: 1) put it in chapter 1, means that many young people and adults with autism are often treated as ‘eternal children’. The irony of this, this study found, is that Sean relates much better to adults than he does to children or to peers of his own age. This is, in fact, far from unusual and resonates strongly throughout the 5 texts reviewed in this study

that were written by authors who have autism. The potential role that committed adults can play in greatly enhancing quality of life for young people with autism is particularly stressed by Temple Grandin and Jim Sinclair. Temple Grandin urges parents to “*incorporate other caring adults*” into the lives of their children, “*people who will take your child places, who can talk with her about their interests, and who even help her discover new ones*” (Grandin & Duffy, 2004: 54). Jim Sinclair adds that “*the autistic child needs the support of adult caretakers and can form very meaningful relationships with those caretakers if given the opportunity*” (Sinclair, 2011: 1).

Those ‘meaningful relationships’ with adult caretakers, as described by Sinclair may, this study contends, amount to very real and sustainable ‘friendships’ in the lives of young people with autism; people who as Grandin describes, can actually tap into the young person’s interests and act as an *advocate* for the young person in question. Such a take on what constitutes ‘friendship’ in the life of a young person with autism stands out in marked contrast to how the concept of friendship has been approached within the mainstream of academic discourse relating to pupils with special educational needs. Many commentators in the ‘inclusion debate’ argue that the inclusion of pupils with autism in mainstream settings will aid them in developing friendships by the ‘normalising effect’ of integrated settings which in turn may promote their acceptance by peers. Guralnick (1990), for instance, suggests that the ‘social competence’ of a child with a disability is the key variable in the development of friendships. Therefore, he proposes that when the social competence of a child improves, so will the child’s social status among peers. Field (1984), like Guralnick, approaches friendship in terms of ‘normalising’ pupils with SEN by looking at issues such as their cognitive and social-adaptive skills. A key advantage of the ‘inclusion’ of pupils with SEN in mainstream settings is, according to this view, the creation of opportunities for observational learning of ‘normal’ behaviour that would not be found in special education settings (Guralnick, 1990).

Whilst there are many advantages to integrated educational settings, the aim of integration- this study strongly contends- should not be to ‘normalise’ the person with autism in order to facilitate their ‘acceptance’ by others. As I have argued in chapter 1, what constitutes a key strength inherent within the ‘autistic condition’- a key *beauty* of the condition which should be *celebrated*- relates to the *uniqueness* and *diversity* of individuals with autism. Yet the ‘knock on effect’ of uniqueness and individuality, is that highly unique individuals (be they

autistic or non-autistic) often do not develop or maintain friendships in the typical way, be it in a special school setting or an integrated school setting, or in society in general. Such people favour quality over quantity, consistency and honesty over ‘popularity’, people who can *deliver* on their promises, people who can appreciate their uniqueness, and help them to develop their strengths. One of Temple Grandin’s most enduring friendships was with her former teacher, William Carlock, who in Temple’s own words “*taught me how to do scientific research, a skill I have used repeatedly in my career and personal life....Mr. Carlock’s kindness and encouragement helped me get through and channelled those fixations into something larger than just myself- a vocation*” (Grandin & Duffy, 2004: 56).

In the credits to ‘Sean’s Journey’ DVD I thank him for “*his trust and his friendship.*” Yet ‘friendship’ is not a concept usually- if ever- applied to the relationship between teacher and pupil. Nonetheless, this study found that a shift in role from that of ‘teacher’ to that of ‘friend’ was a *vital* dynamic in really gaining Sean’s trust, in really moving him forward, and ultimately in finding a way into his world. For him to allow me into his world I had to allow him into mine. Only through mutual self-disclosure, friendship, and the development of trust, could I acquire the ability to ‘read’ Sean’s responses to events as they unfolded. If I were to revisit my positionality within the study, perhaps I became both a ‘friend’ and ‘mentor’ to Sean. According to Temple Grandin, “*a mentor is one of the best kinds of help for those searching for a vocation. In a way, a mentor is a must for adults and teenagers on the autism spectrum because he or she can help them use their fixations in a positive way*” (Grandin & Duffy, 2004: 56).

The ‘4 Cs’: choice, control, challenge and celebration

Developing a friendship with Sean, this study found, entailed an engagement with what I call the ‘4 Cs’. These were *choice, control, challenge* and *celebration*. These 4 principles- this study contends- may help parents and educators to approach the issue of ‘quality of life’ for young people with autism in a positive and forward-looking manner.

Choice

In developing programmes of practice based upon the ‘4 Cs’ it is crucial to be aware of the fact that many children, adolescents, and even adults with autism, may be genuinely terrified of making choices. “*I’m bad at making choices, especially hard ones*”, Sean told me on a

number of occasions throughout the fieldwork. There are very, very few things that I would advocate forcing upon any pupil. However, making choices is one very rare exception. I suggest that people with autism who have a morbid fear of making choices need to be pushed into making them and then instantly praised for making the choice that they made. This should begin, as my case study explored, by giving them ‘little choices’ and developed- over the course of time to gravitate towards making ‘bigger choices’. In the early stages they need to be set up for success (i.e.) one would not ask them to make a choice that, one way or the other, can possibly lead to anything other than a positive outcome. After this, they should be orientated towards the approach advocated by Lawson (2010: 110) which involves helping children with SEN to develop the confidence to choose *“through the meaningful experience of making real choices, being supported in understanding the options available to them, and the consequences of choosing one thing over another.”*

Challenge and control

The concepts of *challenge* and *control* are intimately interrelated with one another. The process of extending opportunities to individuals with autism, to both challenge themselves and to *control their own actions* in the pursuit of conquering challenge, requires what could be described as nothing less than a monumental ‘leap of faith’ on the part of educators and parents/guardians. Yet this study illustrated that when real control was factored into Sean’s life, within contexts as diverse as motor sports, water sports, mountaineering- and even shopping- temporal perception as well as global attention soared, as well as his *urge* to communicate with others.

Yet engaging with concepts of challenge and control, demands a critical engagement with their inevitable counterpart- namely- the concept of risk. ‘Risk’ has been defined by Morgan (2004:18) as *“the likelihood of an event happening with potentially beneficial or harmful outcomes for self and others.”* Seale & Nind (2010) have argued that rather than seeing risk as a provider of opportunity for empowerment, special needs service providers have often struggled to see beyond a perceived lack of competence, and that they often seek or anticipate problems not to solve them, but rather to predict failure. Alaszewski & Alaszewski (2002: 72) add that approaches to risk in centres of special education are often driven more by a desire *“to prevent bad things from happening than a desire to make good things happen.”* And this is understandable. Risk has the power to utterly terrify us. In this study it terrified me. Our instinct as educators- particularly in the field of special education- is not to expose, but to

protect. Yet, as Perske (1972) has argued, experiencing the risk taking of ordinary life is essential for normal human growth and development. Three of the ‘4 Cs’- *choice, control* and *challenge*- are impossible to strive towards without accepting the inevitability of risk, and the fourth ‘C’- *celebration*, can have no real significance in its absence. Ultimately, as I argued in chapter 4, it is crucial that young people with autism are afforded the opportunity for growth that *positive challenge* may provide in helping them to develop their self-confidence, self-efficacy, self-esteem and ultimately, a sense of identity.

Celebration

If we are to accept, as I have argued previously in this chapter, that traditional forms of assessment that inform educational practice in mainstream school settings are insufficient in taking account of an autistic person’s uniquely individual strengths, it would be reasonable to ask what other forms assessment may take. Traditional ‘concepts of assessment’- this study contends- may be replaced by ‘concepts of celebration’- the public celebration of the young person’s achievements in both the school and its wider community. Assessment as it is ‘done to’ a person may stick with that person either positively or negatively. ‘Celebration’, on the other hand- done ‘for’ and ‘with’ a person- always sticks positively.

Sometime after the fieldwork ended, on 18/08/2011, my father Joe led the Irish Prime Minister, an Taoiseach Enda Kenny, to the summit of Carrauntoohil. During the climb Joe told Taoiseach Kenny of Sean’s ascent of Carrauntoohil the previous July and his subsequent donation of 725 Euro to the Vesnova Children’s Orphanage in Belarus. When I told Sean about this the following day he excitedly replied “*You mean he’s heard of my charity work! Does he want to meet me?*” Taoiseach Kenny subsequently sent a personal letter to Sean congratulating him on his bravery and his charity work (see appendix P). All of the correspondences that Sean received from others following the fieldwork, from the letters of commendation from ‘Chernobyl Children’s International’ and Taoiseach Kenny, to the inscription upon the photograph of Cillian Murphy presented to Sean on the occasion of his awards night, were all *celebratory* in nature and were hugely powerful in helping Sean to further develop and maintain a positive sense of identity.

In redressing the issue of ‘assessment’, the creation of ‘performance texts’ for and with young people with autism, this study suggests, may provide an invaluable means of celebrating their achievements in the school and the community. ‘Performance texts’,

Worthen (1998) explains, represent both an investigation into *and* a representation of the phenomenon in question. Leavy (2008) describes a 'performance text' as any experimental text that brings the personal into the public domain by evoking emotional connections. Denzin (2006) characterises the 'performance text' as the single, most powerful way for ethnography to recover yet interrogate the meanings of lived experience, while Leavy (2008) adds that 'performance texts' have the potential to bring academic scholarship to much broader audiences in a complex exchange through which multidimensional meanings emerge. Yet ultimately, the 'performance text' has done something for Sean that I suggest could do something similar for others. It helped him to adopt an outward sense of *identity*. Hussain & Raczka (1997) have stated one of the main objectives of their 'life story work' to be the enablement of the person with a learning disability to develop a sense of identity by talking about his or her ideas, and thoughts and feelings about life. And this, I suggest, is what the 'performance text' has done for Sean. For a young man who is so drawn to narratives, what better way, I suggest, is there to get him to take a positive look at himself than to present him with a narrative; not only a movie, but a real-life movie in which *he himself is the hero*. This had very real implications for Sean in both adopting and expressing an outward sense of identity following the study which is reflected in Sean's personal writing extract on the following page.

What I Like about Ireland 2/2/11

y

My name is Sean Cronin
I am 15 years old.

I live in Woodhaven Fort William
Douglas Cork. I'm a good guy but ^{some} ^{times} lazy

My parents names are
John and Noreen Cronin. I
have 2 brothers named Conor
and Ciaran Cronin. ~~What~~ We
~~are~~ all Irish citizens.

What I like about Ireland
is that I feel very
safe, even when ~~there~~
~~is~~ there ^{are} crimes
being carried out. I think
the Police are working
well and I live in a
clean country with
nice beaches, clean
rivers and nice fields.

We have some great
Play grounds and good
cinemas and our military
are good. We have
some very famous people

x
like Cillian Murphy, Peter
Stringer and ~~Ronan~~ O'Gara
who are friends of my
friend Steve O'Leary.

It ~~is~~ is very interesting
that I met Steve and I
am proud to be Irish. These
are the things I like
about Ireland.

Approaching the ‘condition’ of autism

In chapter 2, I referred to the standard psychiatric definition of autism as it appears in the *‘Diagnostic and Statistical Manual of Mental Disorders’*, the ‘triad of impairment’ as it is commonly known. These impairments are said to be- namely- qualitative impairments in social communication, social interaction, and social imagination, with a restricted range of interests and often stereotyped repetitive behaviours and mannerisms (DSM IV, 1994). The ‘condition’ of autism, this study concludes, amounts to far more than the impairments identified in the above definition of autism. The above-mentioned deficits in the autistic condition, this study contends, do not remain ‘fixed’ throughout the course of an autistic individual’s lifetime. Autism, this study contends, is rather best understood as condition of often brilliant self-accommodation in which autistic people draw upon the most extraordinary powers of self-preservation, imagination and survival to cope with a fragmented, disjointed and often painful world.

Autism as a ‘condition of accommodation’

Exploring autism as a condition of ‘accommodation’ involves adopting a ‘capability approach’ to disability which seeks to replace a ‘within-child’ approach to disability with a relational approach towards disability which does not see disability as being unilaterally biologically determined, but rather addresses the interrelation between individual, social and circumstantial factors in its overall conceptualisation. As Terzi (2005 a: 213-214) puts it, *“impairment, either physical or mental, relates to the loss of some aspect of functioning....disability [however] depends on the design of the physical and social setting [in which the person exists].”*

Autism, as I argued in chapter 2, is essentially a ‘discursively constituted object’. As Grinker (2009: 14) put it *“illnesses may be biological but they are never simply biological.”* As I alluded to throughout chapters 1-3, autism can only be understood *in its totality* by studying autism not only as a bio-genic phenomenon, but by further exploring how individual people *react and accommodate* to the condition- by exploring autism as a ‘relational phenomenon’. People with autism do not choose to be autistic. They do nonetheless choose how to accommodate to the condition. The nature and forms of such accommodations, when

considered seriously- this study contends- may tell us a great deal about ‘what autism is’ beyond clinical, neurological, neuropsychological and cognitive understandings of autism. For instance, to say that people with autism lack imagination would be to ignore the often brilliant accommodations that individuals with autism construct in order to preserve and maintain their identity; accommodations that often draw upon the deepest powers of imagination and creativity. While the ‘executive dysfunction’ theory of autism (Norman & Shallice, 1980) draws our attention towards the difficulties that people with autism often experience in relation to abstract thought, and ‘Theory of Mind’ (Leslie, 1987) draws our attention towards the difficulties that those people may experience in relation to ‘mind reading’, those theories do not take account of how people may actually accommodate to those difficulties.

Appendix B draws attention to a study (Baron-Cohen, 1989) in relation to the ability of children with autism to make appearance-reality distinctions. In the study it was revealed that children with autism found it difficult to identify what a red candle in the shape of an apple actually ‘was’. The same dilemma, this study contends, may be applied to the difficulties that people with autism may encounter in relation to their perception of other people. ‘Theory of Mind’ may be best understood, this study suggests, as a difficulty that people with autism experience in comprehending how objects, and people, can be ‘more than one thing’, or be said to *represent* more than one thing. As previously discussed, in order for Sean to retain people in memory he first needed to ascribe people very identifiable ‘functions’ (for instance he found it difficult to comprehend that Joe was both a mountain climber *and* a teacher and could only retain his role as a ‘famous mountain climber’ in memory). The same difficulty, for Sean, related to the different ‘sides’ of people, including himself. In conversations with Sean, both during and following the period of fieldwork, it became apparent that Sean viewed himself as having only 2 sides to his ‘self’, what he called the ‘good side’ and the ‘bad side’. It also became apparent that he desperately struggled in understanding how other people could have a multiplicity of ‘aspects’ to *their* selves- why they would act differently in different circumstances and situations, or why they would say things that were not directly consistent with statements they had previously made.

This study concedes that pretence may indeed, as Leslie (1987) suggests, be the ‘crucible’ for a ‘theory of mind’, but it further suggests that ‘pretence’ can manifest itself in many different forms for people with autism. Sean’s fictional world of pretence, this study found, was a most

skilful accommodation in attempting to overcome difficulties associated with ‘theory of mind’. By assigning characters different ‘sides’, and creating different ‘versions’ of different characters- such as Aron, Ciara and ‘Sonic the Hedgehog’- he was ingeniously exploring issues relating to *how* and *why* characters, and by association *people*, behave in different ways in different situations, through the medium of invented, exploratory stories and scenarios that reached a remarkable level of depth and complexity. In addition to this he was simultaneously exploring aspects of his own identity; what characters he most wanted to be like- namely the ‘good’ characters like Aron and Alex Raven. The same may be said to be true of Donna Williams’ invented protagonist, Willie. “*The only heart emotion that Willie had*”, Donna tells us, “*was anger....this he channelled into fierce determination, his motivation an ever-clinical, ever-logical sense of justice and equality*” (Williams, 1998: 10).

Autism as a condition of empathy

People like Sean and Donna, and I suggest many, many more people with autism, are best described as ‘utopian’ individuals. Both Sean’s and Donna’s internal worlds reveal an overriding pre-occupation with human, natural and social justice: ‘right’ winning out over ‘wrong’. That same sense of utopianism, that ‘ultra empathy’ for the plight and feelings of others, this study found, coloured Sean’s ‘external reality’ as much as it did his ‘internal reality’. While it may well be true to say that people with autism live within a very ‘black and white’ world in which things are either ‘right’ or ‘wrong’, ‘good’ or ‘bad’- whether that outlook upon life amounts to either a disability or a gift is an entirely subjective and culturally-specific question. Sean’s overriding concerns for the feelings and welfare of other people (and animals), as described throughout the course of chapter 4, paints a picture of autism as being the polar opposite of a deficiency in empathy.

It is not true to say- this study contends- that the more a person with autism constructs systems, the more deficient that person becomes in a capacity for empathy (Baron-Cohen, 2008). Sean lives within a world of systems; brilliantly constructed systems, that help him to understand and comprehend the world around him. Yet he is also one of the most empathic and principled of young people whom I have ever had the pleasure to know. As described in chapter 4, Sean’s deep concern for the ‘welfare of the horses’ should the world ‘flip’ in December 2012, his utter devastation in relation to the feelings of ‘that fly’s family’ (when his father accidentally killed the fly in question), his utter aversion to smoking (which causes

death), as well as his commitment to help ‘the poor children of Russia’ - in the process pushing himself far beyond his own apparent limitations- paints a picture of autism as a *gift*, a condition characterised by not only ‘undiluted directness’ but also by an undiluted ‘honesty’; a uniquely human outlook upon life.

Autism as a relational condition

In the introduction to this thesis I argued that *how people engage* with a person with autism will ultimately dictate whether that person will remain eternally trapped behind a ‘world of glass’, forever disconnected from others, or whether that person may be ‘enticed across the neurological divide’, from the safety of the left hemisphere to the possibility of its right-hand-side counterpart. To ‘reach’ a person with autism- regardless of their age, circumstance or the severity of their impairments, this study concludes- requires a fundamental appreciation that while autism is in many ways a difficult condition- presenting a whole host of challenges to those with autism, their families and their teachers, it is *fundamentally* a ‘condition’ of the most undiluted beauty and honesty.

As Temple Grandin previously alluded to, autism is a ‘withinness’ disability. This leads to a sense of ‘aloneness’, a sense of being ‘cut off’ from the outside world, which- this study contends- people with autism *react to* and *accommodate to* by finding alternative ways to connect both ‘inwardly’ and ‘outwardly’. “*Colour and texture*”, Wendy Lawson tells us, “*are just examples of mediums that connect me to life and to feeling....tunes and music or a gentle low-pitched voice can temporarily relieve moments of fear and anxiety and help me to think and calm down*” (Lawson, 1998: 8). “*My world*”, Donna Williams tells us “*was a spiritual body...my home, my self, my life, my entire system of making sense of that bastard place called ‘the world’.....I could share only so long as nothing I shared or the way I shared it was ‘me’....Carol could laugh in the face of emotions that could not reach her*” (Williams, 1994: 7-9). “*I decided that Carol understood that no-one else was allowed to see me with her and that this was her way of protecting me*” (Williams, 1992: 22).

Regardless of what causes autism (which are without doubt bio-genic factors), helping a child or young person to find a ‘way out’ of autism demands finding a ‘way into’ it *that does not see it or treat it as being ‘wrong’*, but rather as a place of great wonder; a place of the most skilful adaptation, of creativity, of beauty, of purity, and of truth. Once the person with

autism recognises this *attitude*, this *unconditional acceptance* on the part of the other, it may then, this study contends, become possible to build bridges based upon mutual trust, and to develop points of *connection* with the person in question- which while not perhaps conforming to traditional ‘norms’ of communication, may nonetheless serve to connect both worlds in the most powerful of ways.

Autism as a spiritual phenomenon

Autism in western society, since it was first described by Leo Kanner in 1943, has been categorically carved up, again and again, through the field of psychiatry. It has been theorised and re-theorised within the fields of psychology and neuropsychology. It has been clinically, anatomically, biochemically and neurologically investigated with pointed precision across the fields of medical science and neurology. Whilst I am not suggesting for a moment that this multidisciplinary drive to understand ‘what autism is’ has been in any way a bad thing, I *am asking*, what of its meaning? Can autism be appreciated as a ‘condition’ having inherently more scope- more potential- beyond that of a mere intellectual disability?

I began chapter 2 by contrasting the western psychiatric understanding of autism as an ‘intellectual disability’ with the understandings espoused by some alternative cultures which perceive and treat people with autism as being primarily *spiritual beings*. From Israel to the United States, from rural India to Senegal, there are cultures and sub-cultures in the world that have an entirely different take on ‘what autism is’ beyond its western-orientated conceptualisation. I regret that due to the length-specific parameters of this thesis I could not provide a more detailed discussion of autism in various cultures, yet I hope to have illustrated the point that how we view autism in the west is *only one way of viewing it*.

Possessing ‘blessed innocence in the eyes of God’ was how people with autism were described in 16th century Russia. And after my experiences with Sean I can’t help but speculate that this was a far more accurate assessment of autism than we can now offer in the west over five centuries later. This is because 16th century Russian society attempted to capture the *essence* of what autism is beyond the sort of psycho-medical descriptions that have dominated western-oriented discourses since the latter half of the 20th century. When viewed from a paradigm of spirituality and undiluted humanity, as opposed to the chains of disability, it is truly astonishing how the classical western theories around autism become

completely inverted. ‘Theory of mind’ or ‘mentalising’ deficit becomes a capacity for undiluted directness. An inability to deceive becomes the quality of trustworthiness. An inability to lie becomes an unwavering commitment to truth. And an inability to pull information into coherent, contextual wholes becomes a capacity to perceive the *elemental*. Those who can perceive the elemental are individuals who have never known or been seduced by the abstract; those who as Sacks (1985: 240) describes live “*not in a universe, but in a ‘multiverse’ of innumerable, exact, and passionately intense particulars.*” The elemental is what makes reality real. It is a vehicle of mystery, beauty and depth, a path into the emotions and the imagination. The elemental is imbued with feeling and meaning. It readily moves into the aesthetic, the dramatic, the comic, the symbolic; the deepest worlds of art and spirit. Little wonder then, that in certain societies where such human qualities are held in high esteem, children with autism are said to resemble nothing less than the gods and the saints.

Redressing ‘models’ of teaching people with autism

In approaching how we ‘teach children with autism’ professionals look for established, ‘tested’ models, and seek to either repeat those models, or imitate them in some other form. People cling to the *safety* of accepted knowledge. Wing and Siegel, for instance, remain steadfastly wary of the potential benefits of including children with autism in mainstream schools, their faith remaining grounded in established approaches such as ABA and TEACCH to provide an ‘appropriate’ education for children with autism. And on one level they should not be criticised for their views, simply upon the basis that schools have largely failed to experiment with ‘untested’ approaches towards including or integrating pupils with SEN into mainstream settings.

Creating inspired new ‘models of practice’ for pupils with autism, this study contends, should entail not a rejection of all ‘accepted knowledge’ of autism, but rather seek new paths, new avenues, new directions, towards the discovery of ‘new’ knowledge by steering the ‘story of autism’ in new, unexplored directions. The 15 new units for young people with autism currently being developed in the Cork city and county areas, this study contends, should not be based upon the repetition of existing models, but should entail a process of continually ‘raising the bar’ for young people with autism- pushing the boundaries of possibility for and with them- and *advocating for them* as valued members of the school and its wider

community based upon *principles* that seek not to ignore, but rather transcend, accepted ‘knowledge’ of autism.

Muckelbauer (2008: 73), on the topic of ‘imitation and invention’ in relation to ‘models of practice’, has stated that “*while any number of objects or practices might function as models- a literary style, a moral practice, a writing process, a probable action, or an ideal form- the effort to imitate these models has been principally concerned with presenting them in some fashion.*” This, Muckelbauer terms ‘repetition of the same’, “*attempting to identically reproduce the [given] model*” (ibid: 73). This could be said to be the case with the behaviourist principles underpinning ABA. In this ‘first movement’ as he coins it, “*the subject responds to its model as to a determinate content and attempts to produce a copy that internally corresponds to that content; variation then occurs as an external side effect*” (ibid: 73).

The ‘second movement’ which Muckelbauer (2008: 74) identifies, “*only repeats the model by altering it.*” This could be said to be the case with TEACCH. “*The subject*”, Muckelbauer explains, “*responds to its model as to an indeterminate content, a constellation of possible effects, and attempts to produce a copy that will provoke those effects; variation becomes an internal necessity*” (ibid: 74). This he terms- ‘repetition of difference’. Within this process, you may well change the action, but you *don’t change the model*. “*These two different dynamics, therefore*”, he concludes, “*offer two different ways in which subjects might respond to their models in order to repeat them; either as a determinate content (identical reproduction) or as an indeterminate content (differential reproduction)*” (ibid: 74). To affect real change you *have to step outside the model*. This, Muckelbauer coins as a process of ‘*inspiration*’- throwing out all existing models and creating an entirely new approach towards the phenomenon in question. And that- ultimately- is what is required to create new approaches, exemplars or ‘models of practice’ in working with young people with autism.

Autism and the nature of knowledge

There is a kind of knowledge, a knowledge that comes from putting things together from bits. This is the knowledge of what we call ‘facts’. Such knowledge is entirely divorced from context. It concerns knowledge in the public domain- the local train timetable for instance, or mechanical knowledge relating to, for instance, a car engine. The machine is something that

has been put together so it is understandable purely in terms of its parts; the machine is lifeless and its parts are inert- its tappets don't change their nature with their context. The virtue of such knowledge is its certainty- it is *fixed*. It doesn't change from person to person or from moment to moment. It is divorced from context.

Knowledge relating to *people*, however, is entirely different and entirely dependent upon context. "*My knowledge of you*", McGilchrist (2010: 96) professes, "*can be informed by knowing your age, height, and place of birth, but that is not in itself at all what I mean by knowledge of you.*" Every human being that exists does so only in relationships and the multiple contexts in which they emerge. 'Knowledge' of another person essentially involves an *encounter* with that person in a particular context. We say we 'know' someone in the sense that we have experience of him or her, so that we have a 'feel' for who he or she is, as an individual distinct from others. And this kind of knowledge permits a sense of the *uniqueness* of the other.

How we approach acquiring knowledge of a living, human person can never take an approach that is claimed to be fixed or certain. Like the implicit, subliminal, ever-changing, ever-evolving themes embodied within the art form of story, knowledge of *the person* must take account of *context*- the embodied *person*. Approaches towards the acquisition of knowledge come from making distinctions between things. This implies that we can come to an understanding of the nature of any one thing, whatever it might be, only by comparison with something else we already know, and by observing their similarities and differences. However, just as everything changes its nature, however slightly, when it changes its context what we choose to compare something with determines which aspects of it will stand forward and which will recede.

A 'multiplicity of selves'

We all, I believe, have a *multiplicity of selves*. That- *ultimately*- is what Sean taught me. We have a 'cognitive self'- how we think about and perceive the world around us and the world within us. We have an 'interpersonal' self- our own sense of ourselves, the most fragile sense of self, which can be either developed or destroyed by the perceptions and actions of others. We have a physical self- our bodies- that in spite of vulnerability to injury, disfigurement and disability- has the capacity, through the power of the human spirit, to overcome the most

seemingly insurmountable of obstacles. People with disabilities may have an additional self; an ‘autistic self’, a ‘deaf self’ or a ‘blind self’ for instance, which they themselves- and only they themselves- have the right to either accept or reject as constituting an aspect of their ‘self’; *their* personhood. Yet whether they accept or reject it, this study contends that the ‘disabled self’ *is only one aspect of self*. There are far more powerful forms of self, not least of which is the ‘human self.’ This is the form of self that *transcends all other forms of self*. This sense of self is what makes us ‘us’. It embodies all of our beliefs, all of our human spirit and human potential; everything that enables us to transcend the physical, the ‘impossible’. It is what uniquely locates and defines us, our role, our place, our purpose- *where we fit, where we exist*- in the world.

A *multiplicity of selves*, I conclude, exists in every person. The challenge for educators, I suggest, is to create *new contexts*- ‘sites of experience’, ‘frames of reference’- within which the multiplicity of selves can be revealed, nurtured and *celebrated*. And doing this is all about *watching*- and *learning*- in the realisation that knowledge of a person, ‘my knowledge of you’, *is never fixed*. Acquiring meaningful knowledge of a person requires an ‘I-thou’, not an ‘I it’, approach. Context changes action, which affects perception, which shifts judgement, which alters response, which changes outcome. “*Since at least the time of Galileo*”, Bayliss (2008: 11) explains, “*physicists have considered frames of reference, how to communicate between those frames, and how different frames may be more or less useful in [solving] a particular problem.*” An exploration of such ‘frames of reference’ is, I suggest, the only way to create new knowledge- *by creating new knowledge differently*. I would like to conclude by presenting 3 frames of reference; that of a neurologist- Oliver Sacks (1985: 190-191) describing his patient Rebecca, that of a parent- Roy-Richard Grinker (2008: 27)- describing his daughter Isabel, and finally that of a teacher (myself), describing Sean. I will, in conclusion, allow these stories to speak for themselves.

Rebecca

“When I first saw her- clumsy, uncouth, all-of-a-fumble, I saw her merely, or wholly, as a casualty, a broken creature, whose neurological impairments I could pick out and dissect with precision: a multitude of apraxias and agnosias, a mass of sensorimotor impairments and breakdowns, limitations of intellectual schemata and concepts similar to those of a child of eight....The next time I saw her, it was all very different. I didn’t have her in a test

situation, 'evaluating' her in a clinic. I wandered outside- it was a lovely spring day- with a few minutes in hand before the clinic started, and there I saw Rebecca sitting on a bench, gazing at the April foliage quietly, with obvious delight. Her posture had none of the clumsiness which had so impressed me before. Sitting there, in a light dress, her face calm and slightly smiling....she could have been any young woman enjoying a beautiful spring day. This was my human, as opposed to my neurological, vision.

She had done appallingly in the testing- which, in a sense, was designed, like all neurological and psychological testing, not merely to uncover, to bring out deficits, but to decompose her into functions and deficits. She had come apart, horribly, in formal testing, but now she was mysteriously 'together' and composed. Why was she so decomposed before, how could she be so re-composed now? Our tests, our approaches, I thought, as I watched her on the bench- enjoying not just a simple but a sacred view of nature- our approach, our 'evaluations', are ridiculously inadequate. They only show us deficits, they do not show us powers....They had given me no hint of her positive powers, her ability to perceive the real world- the world of nature, and perhaps of the imagination- as a coherent, intelligible, poetic whole.... She showed me how she herself was composed by a natural scene, a scene with an organic, aesthetic and dramatic unity."

Isabel

"Sometimes, at night, Isabel has a hard time falling asleep. It helps her if I sit in a chair in her bedroom. Looking at her then, from across the room, I see two different Isabel's. There is Isabel awake- often hyperactive and isolated- and Isabel asleep, a beautiful child drifting into a calm night. She looks so peaceful and relaxed. When I can hear each breath, I know she's finally fallen asleep, but I sit for a minute more- just to make sure, I tell myself. The truth is, it's nice to be in the same room with her without having to work so hard. Isabel has always been a slim girl, but she has a round face that invites kisses. Before I leave her room I kiss her cheek. I think about how much she has to struggle every day, just to deal with what to her must be chaos. At the end of the day, when I tuck her in, she's not a case of autism. She's simply my daughter."

Sean

It was Monday the 21st of June 2010. It was a beautiful summer's morning. Taking advantage of the weather, myself and Sean headed off to Inchadonny beach for a walk. As we strolled

along the vast, empty, seemingly endless beach, communication no longer seemed to be dependent upon language. It was the 'second movement' of friendship, following on from our walk back from the Granary theatre to the car on the previous Friday. There was too much else going on than to waste our time talking, so we just walked. The tide, which had receded, exposed a vast expanse of landscape enticing freedom and escapism.

Eventually, as we walked along, Sean overtook me. He veered off towards the shoreline where he could hear the lapping of the waves cascading upon the sand. And then he started to pretend. Staring out into the vastness of the southern Atlantic ocean, he looked at his hands and proceeded to make the most beautiful of index movements, gracefully and fluently. His hands and fingers, once again, 'danced'. And in that moment, I think, our worlds met. Then he embarked off to skip along the beach- off into the distance- towards the infinite vastness of the horizon spread out before him- both a child and an adult- but nature doesn't judge. This was the true picture of freedom, of spirituality, of personhood. As I watched Sean skip along the beach in blissful innocence, his individuality, his uniqueness, the beauty of his 'self'- opened up, revealed itself and shone in all its intensity against the backdrop of the magnificence of the landscape, affording me my finest privilege- a glimpse into the elemental- nature- and humanity- one- in its purest form.

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APPENDICES

APPENDIX A- Sean's developmental and early educational history

Note: *The following appendix is based upon a series of interviews that I conducted with John and Noreen Cronin over a one-week period from Tuesday, March 29th 2011. Because of the sensitive and personal nature of our conversation, I did not consider it appropriate to record the dialogue on dictaphone. Rather, I took occasional notes during pauses in conversation. However, the first of many subsequent drafts of what came out of our conversation contained a great many inaccuracies. I owe a sincere debt of gratitude to John and Noreen for editing and proof-reading the many drafts of my account of Sean's developmental history to help me to finally create an edit that can now be presented as being 100% factually accurate.*

Sean Cronin was born on August 9th 1995. There were no complications during pregnancy nor during childbirth, and Sean reached all of the usual infant milestones in a timely fashion. However, at 14 months Sean received his first antibiotic. Exactly one month later, at 15 months, he received the MMR vaccine. Immediately after this Sean began becoming sick regularly, developing significant bowel problems which were examined at St. Finbarr's Hospital, Cork, and later at Portland Street Hospital, London.

Sean's parents, John and Noreen, report that between the ages of 18 and 24 months Sean began to become "*withdrawn, less social, less vocal and more distressed.*" His sleep became disrupted and he became increasingly wakeful at night. John recalls that on the day of Sean's second birthday he "*sat in his bubble car and didn't want people to come near him.*" Despite a visit to their general medical practitioner in which they were told that there was nothing to be concerned about John and Noreen were concerned that this "*just didn't fit*" the reality of what they were seeing. Their son who had acquired 50 words by the time he reached 2 years had only 15 words remaining in his language repertoire by time he reached 3 years of age.

John told me how, from this point on, Sean began physically manipulating his environment and those around him. For example, when John, who would normally sit in the armchair, instead sat on the couch, Sean would lead him by the hand back to the armchair. He was, John explained, "*growing more and more dependent on non-verbal communication and would regularly resort to screaming.*" Meanwhile, when people who he didn't recognise called to the family home, Sean would have severe panic attacks. These panic attacks became even more pronounced and severe when he soon developed a "*morbid fear of cars and traffic*".

John and Noreen recall the period of time when Sean was between 2 and 3 years of age as being a "*nightmare*" as they watched their son literally "*falling to pieces*". With little or no professional advice available to them Noreen sourced a book on child development which outlined typical child development compared to the atypical development of a child with autism. She suspected that Sean's developmental pattern was very similar to the developmental pattern of a child with autism. By this stage Sean was 2 years and 8 months old.

In our conversation John recalled a trip to Schull in West Cork when Sean was three years of age. John described to me how the weather was "*particularly wet*" on that occasion and when Sean got a cold he simply had no resistance to infection, became "*very, very sick*", and

how he and Noreen had to pack up and take him home. Sean subsequently began to get sick more and more frequently and each time, his parents reported, he seemed to be losing more and more developmental milestones. *“He seemed”*, John and Noreen explained to me, *“to be going backwards and regressing faster and faster.”* Finally, in September 1998, after a family holiday in Portugal, Sean once again became *“very, very sick”* with gastroenteritis and was once again admitted to St. Finbarr’s hospital in Cork.

At this point, John and Noreen decided that Sean needed to be assessed. They contacted their local ASD service provider and asked to have Sean assessed for possible autism. However, they were told that Sean would have to be placed on a waiting list and could not be seen until May of the following year because the service provider had the resources to assess no more than one child per week. Noreen explained that she subsequently contacted a private psychologist and *“begged her to see Sean.”* While the private psychologist had a similar waiting list, she was eventually able to offer Sean a cancelled appointment on Christmas week. On December 18th 1998, after a 3 hour assessment, the psychologist concluded with no doubt that Sean had autism in the severe range. The outlook presented to John and Noreen was that Sean was *“low functioning”* and would most likely need institutional care. This was the ‘reality’, the ‘end’ that John and Noreen were asked to accept before Sean had even reached his fourth birthday.

As the New Year approached John and Noreen, with diagnosis in hand, returned to their local service provider to explore the educational options available to Sean. Their initial sense of optimism (borne out of the fact that they were told that there was a ‘class placement’ available for Sean) was quickly quelled by their subsequent realisation that this was not, in reality, a ‘class’ at all, but rather a crèche- a *“minding service.”* Further to that, it would be available to Sean for only 2 hours per week, every Thursday, and it would not be made available to him until July 1999 (due to a staff member being absent on maternity leave).

In the meantime, Noreen’s sister had come across a one-hour BBC documentary on the ‘Son Rise’ programme towards working with children with autism, carried out at the Autism Treatment Centre of America in Sheffield, Massachusetts. Upon viewing this documentary, John and Noreen were *“struck by the similarities in behaviour between the child who was the subject of the documentary, and [their] own son.”* They wasted no time and on February 19th 1999 they departed for America where they both took a course in administering the ‘Son Rise’ programme. Upon their return to Ireland the family living room was converted into a therapy room for Sean. With the support of family and friends, they carried out the ‘Son Rise’ program with Sean for several months and Noreen recalled that *“Sean was much happier if he could stay in the therapy room where he was underaroused and calmer than [they] had seen him in over a year.”*

Around this time, John and Noreen were contacted by a local advocate for families with an autistic child, who herself had a teenage son with severe autism, and who had pioneered the ‘HOPE’ Project in Cork. Part of this support project involved introducing families of a child with autism to other families with a child of similar age and diagnosis. Consequently, Noreen and John met another couple whose son had been diagnosed as severely autistic 6 months before Sean. It was clear in talking to John and Noreen that the support and advice they received from this couple, which they could find nowhere else, was of enormous benefit to them.

What eventually became the ABA school that Sean attended between 1999 and 2008 was a parent-driven initiative that started out in the living room of this couple's home. By 1998 they were catering for 12 children with autism, with 6 attending in the morning and 6 in the afternoon. Through constant parental lobbying, plans were eventually underway to transfer to a unit in a mainstream girls National School in Cork City. When the unit was set up Sean had just turned 4 and had still not been toilet trained. With a very young cohort of children, the first unit was essentially an early intervention centre for teaching children basic self-care skills. In a short space of time all of the children in the unit were successfully toilet trained.

Realising that the limited size of the buildings, which were, and still are, very small, as well as the fact that (it was felt) ABA as a methodology should serve to bring these children beyond it towards some more holistic form of provision in the future, the Parent's Association of this ABA centre set about lobbying for the establishment of a new unit in the Cork city area that would be available for their children when they were to reach 12 or 13 years of age. In early 2008 plans for the unit were finalised, a 'pilot programme', due to enrol 2 pupils- Sean Cronin and Shane Crosby- in its pilot phase.

APPENDIX B- Classifications of Autistic Spectrum Disorders (Adapted from ICD 10, 1993)

1. *F84.0- Childhood Autism*, which is defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in three areas of psychopathology; social interaction, communication, and restricted, repetitive behaviour. All levels of IQ can occur but there is significant global cognitive delay in approximately three-quarters of cases. (F.84.0 includes *Autistic Disorder*, *Infantile Autism*, *Infantile Psychosis*, and *Kanner's Syndrome*)
2. *F84.1- Atypical Autism*, which is differentiated from *Childhood autism* on the basis of impaired development in the 3 areas of psychopathology becoming manifest for the first time only after the age of 3 years' and/or there being insufficient demonstrable abnormalities in one or two of the three areas of psychopathology. There is significant global cognitive delay in most cases. (F.84.1 includes *Atypical Childhood Psychosis* and *Mental Retardation with Autistic Features*)
3. *F84.2- Rett's Syndrome*, which so far reported only in girls, occurs when apparently normal or near-normal early development is followed by partial or complete loss of acquired hand skills and of speech, together with deceleration in head growth, usually with an onset between 7 and 24 months of age, resulting invariably in "severe mental handicap."
4. *F84.3- Other Childhood Disintegrative Disorder*, which occurs when after a period of normal development there follows, over the course of a few months, a definite loss of previously acquired skills in several areas of development, together with the onset of characteristic abnormalities of social, communicative, and behavioural functioning, leading also to "severe mental handicap." (F84.3 includes *Dementia Infantilis*, *Disintegrative Psychosis*, *Heller's Syndrome*, and *Symbiotic Psychosis*)
5. *F84.4- Overactive disorder associated with mental retardation and stereotyped movements*, which is diagnosed on the basis of the combination of developmentally inappropriate severe overactivity, motor stereotypies, and "moderate to severe mental retardation."
6. *F84.5- Asperger's Syndrome*, which is diagnosed based upon the combination of a lack of any clinically significant general delay in language or cognitive development plus, as with autism, the presence of qualitative deficiencies in reciprocal social interaction and restricted, repetitive, stereotyped patterns of behaviour, interests, and activities (F.84.5 includes *Autistic Psychopathy*, and *Schizoid Disorder of Childhood*).
7. *F84.9- Pervasive Developmental Disorder Unspecified (PDD-NOS)* which is diagnosed in cases when an individual fits the general description for pervasive developmental disorders but where due a lack of adequate information, or contradictory findings, the criteria for any of the other F84 codes cannot be met.

APPENDIX C- Cognitive investigations into the social impairments in autism (Adapted from Baron-Cohen [1999])

Area of deficit & author(s) of investigative study/studies	Main finding(s) in relation to children with autism
Making mental-physical distinctions. <i>Baron-Cohen, 1989.</i>	Misunderstanding of how physical objects differ from thoughts about objects, (e.g.) touching a biscuit versus touching a thought about a biscuit.
Making accidental-intentional distinctions. <i>Phillips, 1993.</i>	Difficulty in distinguishing between whether a person intended to do something intentionally or accidentally.
Making appearance-reality distinctions. <i>Baron-Cohen, 1989</i>	Difficulty in distinguishing between what misleading objects look like and what they really are, (e.g.) a red candle in the shape of an apple.
Understanding that seeing leads to knowing. <i>Leslie & Frith, 1988; Baron-Cohen & Goodhart, 1994.</i>	When presented with two dolls, one of whom touches a box and one of whom looks inside a box, they are at chance in identifying which one knows what's inside the box.
Identifying mental state words. <i>Baron-Cohen, Ring, Moriarty, Shmitz, Costa & Ell, 1994.</i>	Picking out words referring to mental states such as “think”, “know”, “imagine”. No difficulty picking out words describing physical states.
Production of mental state words in spontaneous speech. <i>Tager-Flusberg,1992; Baron-Cohen et al, 1996.</i>	From about 18-36 months normally developing children spontaneously use words such as “pretend”, “wish”, “hope” etc. In contrast such words are often absent or occur less frequently in their speech.
Production of spontaneous, pretend play. <i>Baron-Cohen, 1987; Wing, Gould, Yeates & Brierley, 1977; Lewis & Bouchner, 1988.</i>	Impairment in the production of spontaneous, pretend play, as well as confusion about what pretence is for and difficulty in distinguishing between when another is or is not pretending.
Understanding statements that cannot be decoded literally. <i>Happe, 1994.</i>	Awareness of the ‘physical’, actual words uttered but difficulty in inferring the mental states or intentions behind them, particularly in relation to metaphor, sarcasm & irony.
Deception. <i>Baron-Cohen & Cross, 1992; Sodian & Frith, 1992.</i>	Difficulty in deceiving others.
Understanding mentalistic causes of emotion. <i>Baron-Cohen, 1991; Baron-Cohen, Spitz & Cross, 1993.</i>	Difficulty in comprehending belief-based emotions, (e.g.) “John thinks he is going to get a present so he feels happy” is difficult to comprehend. “John gets a present so John is happy” is easier to comprehend.
Recognition of the eye region of the face as indicative of when a person is thinking and what a person might want. <i>Baron-Cohen & Cross, 1992; Baron-Cohen, Campbell, Karmiloff-Smith, Grant & Walker, 1995.</i>	Typically developing children as young as three years use gaze to infer both of these mental states. Children with autism have difficulty in identifying a person who is looking upwards and away as a person who is thinking. They also mostly fail to pick up that gaze can be an indicator of what a person might want.
Passing first and second order false-belief tasks. <i>Baron-Cohen, 1989.</i>	While some children and adults with autism pass first order false-belief tasks (inferring what one person thinks) they often fail second order false-belief tasks (what one person thinks another person thinks).

APPENDIX D- Sample of the 4 levels of analysis of field notes (Day 1)

Original field notes for day 1 (LEVEL 1)

Sean day 1

Date: Tuesday 08/6/2010

Outing destination: Kinsale- walk around shops, boating outing- Kinsale Harbour & the Bandon River on upper deck of open top boat (3.00-4.00), visit to chemist, chips in Dinos

Media used: Camera, video camera

Additional data collection: fields notes

Follow up: Conversation with John & Noreen (5.00-6.00)

Field notes:

On boat very little pretending. Very taken in by his surroundings and asking me a lot to take photos of scenes that appealed to him (eg) sailboats, ducks, the castle, colourful houses etc.

Still the odd question about Father Ted but really engrossed by his surroundings, or at least very calm and relaxed. Could be a few factors here; the motion of the boat, the music in the background (Irish instrumental), the tour tape (info on surroundings and history playing in the background, & the scenery itself- seemed mesmerized by the lapping of the water against the side of the boat.

Interesting conversation about the song playing on the boat which sounded like the 'Lakes Of Pontatrain' learned in school. "Was the song stolen"- again the idea of different versions of things coming up. Taking an idea and reinventing it is not the same as stealing it.

Really conversational about Father Ted but willing to talk about other topics in return.

Definitely taking lessons from the Father Ted narratives'- "Be yourself" story!

Very chatty in chemist when I was buying nicorette. Struck up great conversation with two sales people about the need for the government to ban the sale of cigarettes.

Follow up meeting

The stealing of the song probably came from "A song for Europe" episode of Father Ted. We should involve brothers in the programme, particularly during home-based activities such as music and art.

Steve to source some new DVDS to introduce new narratives

Broken down field notes for day 1 (LEVEL 2)

Day 1- 08/06/2010

Field notes

1. Taken in by wide open spaces (visually interested and engaged)
2. Calmed by the breeze (physically stimulating / calming)
3. Calmed by the rocking of the boat- still, relaxed posture- serene.
4. Taken in by new, different experience
5. "Stolen song"- problem with narratives being similar but distinct entities.
6. Very competent in shared reciprocal conversation- turn taking- his question (FT) and my questions.
7. Extremely focused and directed conversation on a moral issue- ban of cigarettes- initiation of directed conversation in very opinionated way.
8. Using quotes from FT to use in conversation
9. Little pretending

Day 1- Field notes; further consideration (LEVEL 3)

Date: Tuesday 08/6/2010

Outing destination: Kinsale- walk around shops, boating outing- Kinsale Harbour & the Bandon River on upper deck of open top boat (3.00-4.00), visit to chemist, chips in Dinos
Media used: Camera, video camera

Additional data collection: fields notes (written)

Follow up: Interview with John & Noreen (5.00-6.00)

1. Seems very relaxed on the boat- perhaps due to new experience, sensory component (motion, wind, music on boat, visual surroundings). Little expected in terms of language, no physical exertion, familiar with me- good level of trust.
2. As above.
3. As above.
4. As above.
5. Interest in music is new (due to recent exposure to Westlife on the internet)- "is this song stolen" is a typical question for Sean to ask- same as the video games he plays in his head- ideas taken from games he has played and uses parts of them to create new private mental games. Becomes distressed that he is 'stealing' the games however and genuinely doesn't want to 'steal' games anymore. He seems confused that there can be different versions of the same thing (song, game)- similar yet unique in their own right.
6. Will respond to my questions when I respond to his questions relating to his area of interest.
7. He has strong opinions on some adult issues (in this case the government ban on smoking)- can take part in intellectual, directed, highly opinionated discussion when he's allowed to voice his opinion- he is fully certain that he is right and seems determined to convince others he is right.
8. Language from DVD narratives is carried into his own language in a very real way- he seems to be constantly learning language from DVDs & video games, not from people around him. He uses these to generate conversations and sometimes respond to questions using these learned chunks of language. He relies on these chunks of

language to communicate. When he is not using these 'language chunks' his willingness and ability to communicate are very limited. In fact he seems most excited to communicate when he is watching a DVD with another person (1 to 1).

9. While he wasn't pretending as much as he does normally he was nowhere near as stimulated as when he was in control during later activities, such as actually driving a boat. This was a relaxing activity- an enjoyable, non-demanding day. It didn't have any major challenge involved but was an example of a shared, enjoyed activity.

Day 1- Field notes; thematic analysis (LEVEL 4)

Sensory processing

I was, at the outset, very interested in investigating Sean in relation to sensory processing disorders and how he must cope with and adapt to having physical difficulties which often co-exist with autism. I was also interested in observing if as he was given sensory stimulation- on the boat on this occasion, would he 'pretend' less (ie) could his pretending be tackled to some degree on a 'physical' level? Could the rocking motion of the boat in some way provide the same stimulation /self regulation that rocking provides for many autistic people, except in this case in a more socially enjoyable context? It quickly became apparent that it would be impossible to really test this hypothesis within the context of this research project, such an investigation would be moving away from the real crux of the project which is concerned primarily with Sean in relation to communication and personhood.

That said, it should be noted that he does seem to respond very well to activities in which he is rocked / moved in a way that does not require any physical exertion on his part.

Cognitive processing- the importance of narrative and pretence

What has always fascinated me about Sean is the way in which he absorbs information (narratives relating to DVDs and video games), processes information (as seen through his drawing), and communicates this information to others through questions ("Wasn't it funny when..."). However, it was always very difficult to get an idea of how he actually processes the information as his drawings (over the first 2 years of the in-school programme) were extremely fragmented, symbolic (relating to single characters, flags and symbols etc). He was also very locked into his own personal 'disaster game' which meant he often went days without attempting to communicate with anyone. At this time the only form of communication was what he was drawing, and which of those drawings he would allow me to see. He was terrified that I would be shocked which was unsurprising since many of his drawings were frightening to look at, often being visually terrifying hybrids of characters from video games. His drawings also showed a preoccupation heaven, hell, the devil, 'satan', Jesus and death. The conclusion I came to was that if Sean has the type of mind (as I still believe he does) that will completely absorb every new narrative he is interested in, process it, and most importantly believe it, he is very much at risk of psychological damage if he is exposed to the wrong type of narrative. An interview carried out with Sean (conducted and recorded by myself and my colleague Loretta O'Sullivan- 14/04/2010) just before the commencement of this research project recorded Sean as saying the following:

Sean: "I hate chatting Loretta but I'm fine. My mind is broken Loretta. It's when your mind gets out of control, my mind gets out of control in class. When you try to wake me up I get

completely shocked. I get completely shocked. I get completely creeped out. I see different pieces from movies.”

Loretta: “What scenes from what movies?”

Sean gets upset and will not answer Loretta’s question. He goes back into a pretend.

Loretta:” Tell me Sean, what are you pretending at the moment?”

Sean: “Alex Raven, a name I just made up. He’s a male. He’s a good guy. He was a taxi driver until New York was invaded by monsters, insect-like monsters, big green trolls. It’s a pretty big invasion. Alex escaped with his family on a plane.” *Sean uses his thumb and forefinger to show the plane leaving.* “His wife’s name is Maria, his daughter’s name is Emily, and his son’s name is....” *Sean becomes upset and does not say the son’s name.* “The aliens came from another world called dragon world, most of the population of New York got killed. Listen Loretta, I feel guilty, so, so guilty that I made those people die and I had to tell that bad thing.”

Loretta: “Do I upset you when I interrupt your pretend?”

Sean: “The more you try to tell me wake up the worse my pretending gets. It’s like when you have a nightmare and you’re interrupted, the nightmare just gets worse.”

This interview, which was one in a series of interviews carried out by Loretta and myself with Sean between March and May 2010 was, in retrospect, one of the most significant as for the first time:

- Sean directly communicated to us how he felt about ‘pretending’ (imagining out) the narrative.
- He revealed that he is not always in control of what he is pretending and can become extremely frightened and upset during the process.
- He seemed to suggest that he cannot come out of a pretend until he has mentally played the narrative through in full.
- He revealed that he feels directly responsible for what transpires in the narratives (ie) he is not simply somebody imagining something out but *by* imagining it out he feels he is directly complicit in it.

A follow up meeting with Sean’s parents revealed that the narrative, and the fear Sean experienced as a result most likely came from a scene from the movie “Avatar” which Sean was shocked by at home. (This made sense as Sean had recently been too terrified to enter a DVD store with his classmates on a class outing as there was an ‘Avatar’ poster on the wall) The conclusion of our meeting was that Sean’s time spent playing video games at home would be reduced and we would try to supplement this with more light hearted DVDs.

The two DVD box sets I chose were ‘Fawlty Towers’ and ‘Father Ted’, the latter of which he chose to watch again and again. My main reason for choosing these narratives was that I could understand them myself (I had no clue about his video games) so if my hypothesis was correct; and he did indeed most comfortably communicate through DVD based narratives, at least I would be able to reciprocate that communication and further investigate how exactly he uses these narratives both in terms of acquiring language and developing social understanding.

Out on the boat, our shared interest in ‘Father Ted’ allowed shared, and enjoyable, communication to take place. It allowed Sean to *generate conversation*- (ie) he could strike up a conversation using ‘Father Ted’ as a tool where otherwise he would be completely incapable of generating a conversation in the absence of a concrete, tangible narrative to generate it about.

It also allowed me to *maintain conversation* with Sean. ‘Turn taking’ (I’ll answer your question if you answer mine’) seems quite simple but I have found it to be (and still find it to be) extremely effective in maintaining conversation with Sean.

Personality and principles

Sean’s highly directed conversation in the pharmacy was a typical example of how Sean can enter very intellectual, adult-orientated conversations when the subject matter is something he believes strongly in (Sean will often approach strangers he sees smoking and will tell them to stop- which has gotten him in trouble a couple of times). One could argue that his insistence on always being right may be explained through ‘theory of mind’ deficit- being only able to see things from his own point of view, and being unable to understand the mental states of others;- and granted, Sean does experience difficulty in this area. However, Sean is a highly principled person who believes strongly in a number of issues, some of which are transient (such as the instance in 2008 when he insisted to the Irish minister of foreign affairs (who visited the unit in school) that he had to “stop those Somali pirates”), and some have been with him since I have known him (such as his preoccupation with caring for the environment and world peace). The point is that Sean is committed entirely to the principle of ‘good’. His drawings (especially those which he drew in the first 2 years of the programme) reveal a continual investigation into good versus evil, and these drawings which were fairly direct (albeit fragmentary) snapshots of what was taking place in his mind at a given time, revealed that Sean undertook a private journey (using his pretending) where he invented his own mental video game (lasting months) wherein a central protagonist, created by Sean, went through a series of ‘levels’ (in the same way video games are structured) within which the protagonist came into contact with a number of ‘good and ‘evil’ characters. Although Sean was unwilling to discuss his mental journey in detail, what he did say strongly suggested that he was trying to discover what truly defined ‘good’ and ‘evil’. In addition, the drawings of his central protagonist who he called ‘Aron’ suggested that Sean was trying to figure out if Aron could be both good and bad, if he could have 2 sides to him. For instance, one drawing depicts Aron as half man, half dragon. One of Sean’s most telling drawings is that of Aron’s face with a line drawn down the middle. The shape of the eyebrow on the left hand side of the face depicts the bad side of Aron, and the eyebrow on the right hand side depicts his good side. In a rare moment when Sean actually spoke to me about Aron, he pointed to the right hand section of Aron’s face and said “I’m going to choose the good side.”

Sean’s ‘pretending’ (where he uses his fingers and thumbs to help him as he plays out his internal mental narratives), as investigated through the drawings he produced while ‘pretending’, cannot and should not be explained as ‘stimming’ due to sensory or cognitive deficit. It is, in fact, a tool that Sean uses to try to make sense of the world around him, and primarily how people relate to other people in society. In addition, the key point to be made is that underlying the ‘pretending’ has been, and still is, a deeply ingrained personal sense morality, humanity and purpose. He does not pretend for the sake of it; he uses it as a means of investigating what is good / right and what is bad / wrong. He then directly applies this

learning to social situations as in the case of the conversation in the pharmacy. He uses 'pretending' to try to learn how he and others can be good and then tries to apply this to the real world.

The fact that Sean is so fastidiously committed to the principle of 'good' can only, in my view, be explained with reference to his innate *personality* which has certainly been influenced by his family circle and key individuals in his life. That is to say that underlying all the surface features of autism lies a central person, a human being whose nature and personality predisposes him to acting primarily in the interests of others if given the opportunity.

Yet the 'Triad of Impairment' model can by its nature go no further than describing Sean's drawings as representing a 'restricted range of interests' from an internal world. Clinical research has not, as yet, investigated 'stimming' as being something which may be more significant than involuntary physical responses to the sensory deficits associated with autism. In addition, all of the dominant paradigms in cognitive psychology (such as 'Theory of Mind' / 'Mindblindness' and 'Empathizing-systemizing' theories) and neuropsychology (such as the 'Weak Central Coherence', 'Executive Dysfunction' and 'Magnocellular' theories) go no way towards factoring in *personality* as a significant part of painting a neurological, clinical or cognitive picture of a person with autism. The deficit nature of dominant, and often stereotyped understandings around autism; and in particular the triad of impairment model has real and serious implications for educational practice in Ireland. In Sean's case (in relation to his primary ABA schooling), the 'Applied Behaviour Analysis' educational model (which is heavily influenced by the 'Triad of Impairment' model) sought to eliminate Sean's pretending (limiting him to pretending in the toilet only) in the hope that if pretending was eliminated (which it never was) through reward and punishment, Sean would naturally tend 'communicate' more. Such thinking was, in my view, seriously skewed. The conversation in the pharmacy (and many other such adult conversations which took place over the course of the field work) demonstrated that Sean can and will interact occasionally in a very adult way when the adult and those around him do not try to stop him from 'pretending' and accept this behaviour of what constitutes him as a person.

APPENDIX E - Extracting themes for each day of fieldwork

Day 1- 08/06/2010

Narrative, literalness and complicity (Day 1- 08/06/2010)
Pretending and self-consciousness (Day 1- 08/06/2010)
Pretending as a learning mechanism (Day 1- 08/06/2010)
The child-adult issue (Day 1- 08/06/2010)
Personality and principles (Day 1- 08/06/2010)
Narrative and language acquisition (Day 1- 08/06/2010)
The mechanics of narrative processing (Day 1- 08/06/2010)
Narrative and communication (Day 1- 08/06/2010)

Day 2- 09/06/2010

Investigation into characters (Day 2- 09/06/2010)
Motivation and purpose (Day 2- 09/06/2010)
Self-esteem (Day 2- 09/06/2010)
The mechanics of narrative processing (Day 2- 09/06/2010)
Narratives and literal interpretation (Day 2- 09/06/2010)
Linking people (Day 2- 09/06/2010)
Linking characters (Day 2- 09/06/2010)
Investigation into people (Day 2- 09/06/2010)
Investigation into characters (Day 2- 09/06/2010)
Self confidence (Day 2- 09/06/2010)
The importance of purpose and the regulation of time (Day 2- 09/06/2010)
Self-esteem (Day 2- 09/06/2010)

Day 3- 10/06/2010

Visual memory (Day 3- 10/06/2010)
Multiple narratives in the pretending process (Day 3- 10/06/2010)
Narrative and surface appeal (Day 3- 10/06/2010)
Narrative and the generation of social interests (Day 3- 10/06/2010)
The importance of narrative reaching an endpoint (Day 3- 10/06/2010)
Narrative, emotional engagement and communication (Day 3- 10/06/2010)
Receptive language (Day 3- 10/06/2010)
Focus on a single narrative during its internalisation (Day 3- 10/06/2010)
Visual and phonographic memory (Day 3- 10/06/2010)
Visual memory (Day 3- 10/06/2010)
The surface accessibility of narrative (Day 3- 10/06/2010)
Focus on a single narrative during its internalisation (Day 3- 10/06/2010)
Multiple narratives during the pretending process (Day 3- 10/06/2010)
Narrative, the generation of interest and the implications for communication (Day 3- 10/06/2010)

Day 4- 11/06/2010

Withdrawal of choice- negative effects (Day 4- 11/06/2010)
Hypochondria and environment (Day 4- 11/06/2010)
Lack of confidence in making choices (Day 4- 11/06/2010)
The importance of granting and encouraging choice (Day 4- 11/06/2010)
Hypochondriac fears (Day 4- 11/06/2010)
Hypochondria and the literalness of narrative (Day 4- 11/06/2010)
Inflexibility of thought (Day 4- 11/06/2010)
Directness of language- communicative intent and the responses of others (Day 4- 11/06/2010)

Day 5- 14/06/2010

Unexpected outstanding performance when granted control (Day 5-14/06/2010)
Control and the disappearance of pretending (Day 5-14/06/2010)
Control and the regulation of time (Day 5-14/06/2010)
Control and challenging ones own assumptions (Day 5-14/06/2010)
Control and the application of focus (Day 5-14/06/2010)
The perceptions of activity leaders (Day 5-14/06/2010)

Day 6- 15/06/2010

Multiple narratives during the pretending process (Day 6- 15/06/2010)
The power of narrative memory(Day 6- 15/06/2010)
Pretending and listening (Day 6- 15/06/2010)
Echolalia as a learning response (Day 6- 15/06/2010)
Multiple narratives during the pretending process (Day 6- 15/06/2010)
Pretending and judgement (Day 6- 15/06/2010)
Multiple narratives during the pretending process (Day 6- 15/06/2010)
Petty mal seizures (Day 6- 15/06/2010)

Day 7- 16/06/2010

The child-adult issue (Day 7- 16/06/2010)
The cultural ideology of our dominant local service provider (Day 7- 16/06/2010)

Day 8- 17/06/2010

The absence of control and the absence of attention (Day 8- 17/06/2010)
The importance of activity leader's perceptions (Day 8- 17/06/2010)
The 'transformative effect' and horse riding (Day 8- 17/06/2010)
The transformative effect and the primacy of interest (Day 8- 17/06/2010)

Day 9- 18/06/2010

Skill in comprehending complex narratives (Day 9- 18/06/2010)
The child-adult issue (Day 9- 18/06/2010)
The importance of newness of experience (Day 9- 18/06/2010)
Conforming to difficult social-behavioural norms (Day 9- 18/06/2010)

The importance of narrative reaching an endpoint (Day 9- 18/06/2010)
The surge in post-activity communication / 'transformative effect' (Day 9- 18/06/2010)

Day 10- 21/06/2010

Control and increasing communication (Day 10- 21/06/2010)
Sensory / spiritual experience (Day 10- 21/06/2010)
The surge in post-activity communication / 'transformative effect' (Day 10- 21/06/2010)

Day 11- 22/06/2010

Investigation into people and the formation of friendship through acceptance (Day 11- 22/06/2010)

Day 12- 23/06/2010

Narrative and communication (Day 12- 23/06/2010)

Day 13- 01/07/2010

Narrative and surface accessibility and appeal (Day 13- 01/07/2010)
Looking forward to upcoming new experiences (Day 13- 01/07/2010)
Musical narrative- initial intensity of investigation (Day 13- 01/07/2010)
Musical narrative and pretending (Day 13- 01/07/2010)
Musical narrative, the broadening of interest and emotional engagement (Day 13- 01/07/2010)
Musical narrative in a social context (Day 13- 01/07/2010)
Appropriate responses to socially demanding situations (Day 13- 01/07/2010)
The linking of people (Day 13- 01/07/2010)

Day 14- 02/07/2010

The child-adult issue and the issue of friendship (Day 14- 02/07/2010)
Pretending and negative self-concept (Day 14- 02/07/2010)
Lack of confidence in making choices (Day 14- 02/07/2010)
Control and challenging ones own assumptions (Day 14- 02/07/2010)
The surge in post-activity communication / 'transformative effect' (Day 14- 02/07/2010)

Day 15- 05/07/2010

Multiple narratives during the pretending process (Day 15- 05/07/2010)
The child-adult issue (Day 15- 05/07/2010)
The non-transference of communicative drive (Day 15- 05/07/2010)

Day 16- 06/07/2010

Investigation into famous people (Day 16- 06/07/2010)
Pretending and communication (Day 16- 06/07/2010)
Petty mal seizures (Day 16- 06/07/2010)
General soaring in alertness over time (Day 16- 06/07/2010)

Phonographic memory (Day 16- 06/07/2010)
Linking famous people to ordinary people (Day 16- 06/07/2010)
The desire for control (Day 16- 06/07/2010)
Withdrawal of control- negative effects (Day 16- 06/07/2010)
Control and challenging ones own assumptions (Day 16- 06/07/2010)
The importance of activity leader's perceptions (Day 16- 06/07/2010)
Unexpected outstanding performance when granted control (Day 16- 06/07/2010)

Day 17- 07/07/2010

Musical narrative in a social context (Day 17- 07/07/2010)
Musical narrative and pretending (Day 17- 07/07/2010)
The surge in post-activity communication / 'transformative effect' (Day 17- 07/07/2010)
Musical narrative and human social connection (Day 17- 07/07/2010)

Day 18- 08/07/2010

Relationship with siblings (Day 18- 08/07/2010)

Day 19- 09/07/2010

Motivation and purpose (Day 19- 09/07/2010)
Empathy for others (Day 19- 09/07/2010)
Overwhelming empathy for others (Day 19- 09/07/2010)
Fear of death (Day 19- 09/07/2010)

Day 20- 12/07/2010

Looking forward to upcoming new experiences (Day 20- 12/07/2010)
General soaring in patience and lack of rigidity over time due to the granting of choice (Day 20- 12/07/2010)
Hypochondria and environment (Day 20- 12/07/2010)

Day 21- 13/07/2010

General social normalisation over time (Day 21- 13/07/2010)
Shared control, mutual trust, relaxation, normalisation and friendship (Day 21- 13/07/2010)

Day 22- 14/07/2010

Relationship with siblings (Day 22- 14/07/2010)

Day 23- 20/07/2010

General social normalisation over time (Day 23- 20/07/2010)
Lack of confidence in making choices (Day 23- 20/07/2010)
Looking forward to upcoming new experiences (Day 23- 20/07/2010)
The nature of purpose, personality and employment(Day 23- 20/07/2010)

Day 24- 21/07/2010

General social normalisation over time (Day 24- 21/07/2010)

Day 25- 22/07/2010

Directness of language- communicative intent and the responses of others (Day 25- 22/07/2010)

The literalness of narrative (Day 25- 22/07/2010)

The development of trust and friendship (Day 25- 22/07/2010)

Directness of language- communicative intent and the responses of others (Day 25- 22/07/2010)

Sean's physical 'limitations' (Day 25- 22/07/2010)

Sensory / spiritual experience (Day 25- 22/07/2010)

Day 26- 23/07/2010

Investigation into people (Day 26- 23/07/2010)

Sean's physical 'limitations' (Day 26- 23/07/2010)

The regulation of time (Day 26- 23/07/2010)

Hidden intelligence (Day 26- 23/07/2010)

The importance of activity leader's perceptions and the 'child-adult issue' (Day 26- 23/07/2010)

Day 27- 26/07/2010

Relationship with siblings (Day 27- 26/07/2010)

Day 28- 27/07/2010

The linking of famous people with normal people (Day 28- 27/07/2010)

The emotional significance of linkages with famous people (Day 28- 27/07/2010)

Relationship with siblings (Day 28- 27/07/2010)

Day 30- 29/07/2010

'Frames of reference' (Day 30- 29/07/2010)

Relationship with siblings (Day 30- 29/07/2010)

Personal engagement in the research process (Day 30- 29/07/2010)

Day 31- 30/07/2010

Increasing independence in safe environments (Day 31- 30/07/2010)

Control and challenging ones own assumptions (Day 31- 30/07/2010)

APPENDIX F- Grouping themes into wider themes

Narrative

Narrative, literalness and complicity (Day 1- 08/06/2010)
Narrative and language acquisition (Day 1- 08/06/2010)
The mechanics of narrative processing (Day 1- 08/06/2010)
Narrative and communication (Day 1- 08/06/2010)
The mechanics of narrative processing (Day 2- 09/06/2010)
Narratives and literal interpretation (Day 2- 09/06/2010)
Multiple narratives in the pretending process (Day 3- 10/06/2010)
Narrative and surface appeal (Day 3- 10/06/2010)
Narrative and the generation of social interests (Day 3- 10/06/2010)
The importance of narrative reaching an endpoint (Day 3- 10/06/2010)
Narrative, emotional engagement and communication (Day 3- 10/06/2010)
Focus on a single narrative during its internalisation (Day 3- 10/06/2010)
The surface accessibility of narrative (Day 3- 10/06/2010)
Focus on a single narrative during its internalisation (Day 3- 10/06/2010)
Multiple narratives during the pretending process (Day 3- 10/06/2010)
Narrative, the generation of interest and the implications for communication (Day 3- 10/06/2010)
Skill in comprehending complex narratives (Day 9- 18/06/2010)
The importance of narrative reaching an endpoint (Day 9- 18/06/2010)
Narrative and communication (Day 12- 23/06/2010)
Narrative and surface accessibility and appeal (Day 13- 01/07/2010)
Musical narrative- initial intensity of investigation (Day 13- 01/07/2010)
Musical narrative and pretending (Day 13- 01/07/2010)
Musical narrative, the broadening of interest and emotional engagement (Day 13- 01/07/2010)
Musical narrative in a social context (Day 13- 01/07/2010)
Musical narrative in a social context (Day 17- 07/07/2010)
Musical narrative and pretending (Day 17- 07/07/2010)
Musical narrative and human social connection (Day 17- 07/07/2010)
The literalness of narrative (Day 25- 22/07/2010)

Pretending

Pretending and self-consciousness (Day 1- 08/06/2010)
Pretending as a learning mechanism (Day 1- 08/06/2010)
Multiple narratives during the pretending process (Day 6- 15/06/2010)
Pretending and listening (Day 6- 15/06/2010)
Multiple narratives during the pretending process (Day 6- 15/06/2010)
Pretending and judgement (Day 6- 15/06/2010)
Multiple narratives during the pretending process (Day 6- 15/06/2010)
Petty mal seizures (Day 6- 15/06/2010)
Multiple narratives during the pretending process (Day 15- 05/07/2010)
Pretending and communication (Day 16- 06/07/2010)
Petty mal seizures (Day 16- 06/07/2010)

The child-adult issue

Hidden intelligence (Day 26- 23/07/2010)

The child-adult issue (Day 1- 08/06/2010)

The child-adult issue (Day 7- 16/06/2010)

The child-adult issue (Day 9- 18/06/2010)

The child-adult issue (Day 15- 05/07/2010)

The importance of activity leader's perceptions and the 'child-adult issue' (Day 26- 23/07/2010)

Personality and principles

Personality and principles (Day 1- 08/06/2010)

Empathy for others (Day 19- 09/07/2010)

Overwhelming empathy for others (Day 19- 09/07/2010)

The nature of purpose, personality and employment (Day 23- 20/07/2010)

Investigation

Investigation into characters (Day 2- 09/06/2010)

Investigation into people (Day 2- 09/06/2010)

Investigation into characters (Day 2- 09/06/2010)

Investigation into famous people (Day 16- 06/07/2010)

Investigation into people (Day 26- 23/07/2010)

Motivation and purpose

Motivation and purpose (Day 2- 09/06/2010)

Motivation and purpose (Day 19- 09/07/2010)

Self-esteem / self concept

Self-esteem (Day 2- 09/06/2010)

Self-esteem (Day 2- 09/06/2010)

Pretending and negative self-concept (Day 14- 02/07/2010)

Linking

Linking people (Day 2- 09/06/2010)

Linking characters (Day 2- 09/06/2010)

The linking of people (Day 13- 01/07/2010)

Linking famous people to ordinary people (Day 16- 06/07/2010)

The linking of famous people with normal people (Day 28- 27/07/2010)

The emotional significance of linkages with famous people (Day 28- 27/07/2010)

Self-confidence

Self confidence (Day 2- 09/06/2010)

The regulation of time

The importance of purpose and the regulation of time (Day 2- 09/06/2010)

The regulation of time (Day 26- 23/07/2010)

Memory

Visual memory (Day 3- 10/06/2010)

Visual and phonographic memory (Day 3- 10/06/2010)

Visual memory (Day 3- 10/06/2010)

The power of narrative memory (Day 6- 15/06/2010)

Phonographic memory (Day 16- 06/07/2010)

Language

Receptive language (Day 3- 10/06/2010)

Directness of language- communicative intent and the responses of others (Day 4- 11/06/2010)

Echolalia as a learning response (Day 6- 15/06/2010)

Directness of language- communicative intent and the responses of others (Day 25- 22/07/2010)

Directness of language- communicative intent and the responses of others (Day 25- 22/07/2010)

Choice

Withdrawal of choice- negative effects (Day 4- 11/06/2010)

Lack of confidence in making choices (Day 4- 11/06/2010)

The importance of granting and encouraging choice (Day 4- 11/06/2010)

Lack of confidence in making choices (Day 14- 02/07/2010)

Lack of confidence in making choices (Day 23- 20/07/2010)

Hypochondria

Hypochondria and environment (Day 4- 11/06/2010)

Hypochondriac fears (Day 4- 11/06/2010)

Hypochondria and the literalness of narrative (Day 4- 11/06/2010)

Fear of death (Day 19- 09/07/2010)

Hypochondria and environment (Day 20- 12/07/2010)

Inflexibility of thought

Inflexibility of thought (Day 4- 11/06/2010)

Control

Unexpected outstanding performance when granted control (Day 5-14/06/2010)

Control and the disappearance of pretending (Day 5-14/06/2010)

Control and the regulation of time (Day 5-14/06/2010)

Control and the application of focus (Day 5-14/06/2010)

The absence of control and the absence of attention (Day 8- 17/06/2010)
Control and increasing communication (Day 10- 21/06/2010)
The desire for control (Day 16- 06/07/2010)
Withdrawal of control- negative effects (Day 16- 06/07/2010)
Unexpected outstanding performance when granted control (Day 16- 06/07/2010)

Challenging one's own assumptions

Control and challenging ones own assumptions (Day 5-14/06/2010)
Control and challenging ones own assumptions (Day 14- 02/07/2010)
Control and challenging ones own assumptions (Day 16- 06/07/2010)
Personal engagement in the research process (Day 30- 29/07/2010)
Control and challenging ones own assumptions (Day 31- 30/07/2010)
Increasing independence in safe environments (Day 31- 30/07/2010)

Perceptions of activity leaders

The perceptions of activity leaders (Day 5-14/06/2010)
The importance of activity leader's perceptions (Day 8- 17/06/2010)
The importance of activity leader's perceptions (Day 16- 06/07/2010)

Dominant service provider ideology

The cultural ideology of our dominant local service provider (Day 7- 16/06/2010)

The transformative effect

The 'transformative effect' and horse riding (Day 8- 17/06/2010)
The transformative effect and the primacy of interest (Day 8- 17/06/2010)
The surge in post-activity communication / 'transformative effect' (Day 9- 18/06/2010)
The surge in post-activity communication / 'transformative effect' (Day 10- 21/06/2010)
The surge in post-activity communication / 'transformative effect' (Day 14- 02/07/2010)
The surge in post-activity communication / 'transformative effect' (Day 17- 07/07/2010)

Newness of experience

The importance of newness of experience (Day 9- 18/06/2010)

Conforming to difficult socio-behavioural norms

Conforming to difficult social-behavioural norms (Day 9- 18/06/2010)
Appropriate responses to socially demanding situations (Day 13- 01/07/2010)

Sensory / spiritual experience

Sensory / spiritual experience (Day 10- 21/06/2010)
Sensory / spiritual experience (Day 25- 22/07/2010)

Looking forward to upcoming experiences

Looking forward to upcoming new experiences (Day 13- 01/07/2010)

Looking forward to upcoming new experiences (Day 20- 12/07/2010)

Looking forward to upcoming new experiences (Day 23- 20/07/2010)

General improvement over time

General soaring in alertness over time (Day 16- 06/07/2010)

General soaring in patience and lack of rigidity over time due to the granting of choice (Day 20- 12/07/2010)

General social normalisation over time (Day 21- 13/07/2010)

Shared control, mutual trust, relaxation, normalisation and friendship (Day 21- 13/07/2010)

General social normalisation over time (Day 23- 20/07/2010)

General social normalisation over time (Day 24- 21/07/2010)

Relationship with siblings

Relationship with siblings (Day 18- 08/07/2010)

Relationship with siblings (Day 22- 14/07/2010)

Relationship with siblings (Day 27- 26/07/2010)

Relationship with siblings (Day 28- 27/07/2010)

Relationship with siblings (Day 30- 29/07/2010)

Sean's physical 'limitations'

Sean's physical 'limitations' (Day 25- 22/07/2010)

Sean's physical 'limitations' (Day 26- 23/07/2010)

Frames of reference

'Frames of reference' (Day 30- 29/07/2010)

Friendship

Investigation into people and the formation of friendship through acceptance (Day 11- 22/06/2010)

The child-adult issue and the issue of friendship (Day 14- 02/07/2010)

The non-transference of communicative drive (Day 15- 05/07/2010)

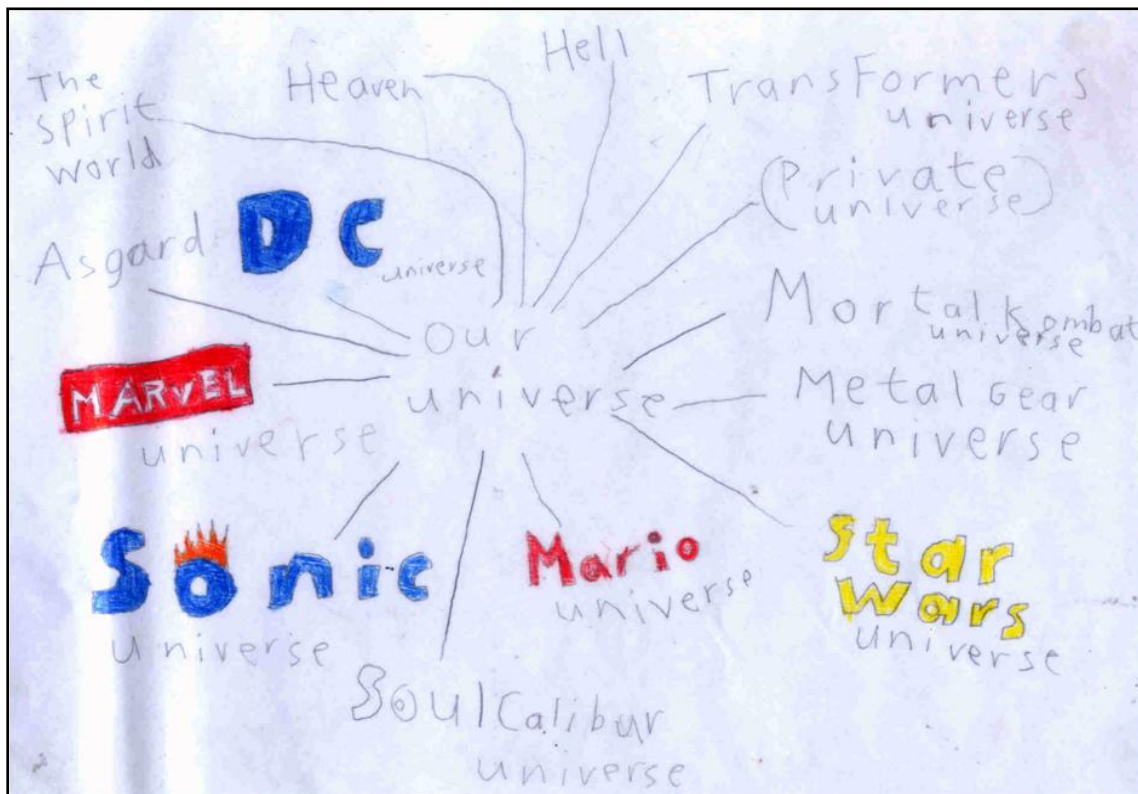
The development of trust and friendship (Day 25- 22/07/2010)

APPENDIX G- Sean's internal world of pretence and the 'Aron Narratives'

In September 2008, when Sean first entered my programme, he instantly established himself as something of an enigma. On the one hand he had fleeting moments wherein he could launch into extremely lucid- albeit fragmented- conversations with me. Yet on the other hand he went through days in which he would remain self-isolated, closed off, happier within his own world of fantasy than in making contact with the outside world. He was the kind of child however that, no matter how difficult he was to reach, always hit you with a sense of charm, humanity and warmth that would constantly keep one searching for some way in.

One day, entirely at my wits ends, I just sat down with Sean. Verbal communication was a 'non-starter' at this point so I just handed him a blank piece of paper, and a pencil, and simply said "Sean, draw for me what's going on in your head." What Sean produced in response to this question, without saying a word (in late January 2009) came as a surprise to me, to say the least. Figure A 'Our Universe', which he produced on the spot, was a mapping out of exactly how Sean perceived *his world* at the time; a multiplicity of universes composed of video games (the Mario, Sonic, Mortal Combat, Metal Gear & Star Wars universes), comics (the Marvel and DC universes), DVDs (Transformers universe), as well as a number of spiritual universes (the Spirit World, Heaven and Hell). Finally there was Sean's 'Private Universe'- one reserved only for Sean himself.

Figure A- 'Our Universe'



This mapping of Sean's world was followed by pictures of 'Aron', an invented hero who travelled between the universes presented in figure A. 'Aron' was Sean's external protagonist, an 'imaginary friend' if you like, one who in my view represented an extremely complex mixed projection of both Sean himself and the characteristics of fictional characters,

as well as religious icons, who day after day he was incessantly running through his mind. And as, day after day, I examined Sean's drawings- the only means by which I could try to communicate with him- I realised that Aron lived within a *deeply personal, internal narrative journey*, one which Sean called 'Disaster Game', 'Invasion Game', and 'Imagination Game'.

Figures B & C- 'Aron'



Figures B and C above (both created in late February 2009) are both depictions of Aron. Figure B depicts Aron in semi-human form. In this drawing Aron appears to be human, but he is, in fact, a hybrid character- internally half man-half dragon- prepared for battle. Figure C again depicts the seemingly normal- but hybrid- Aron, but this time with his lower limbs turned into rockets to enable flight in battle.

Figures D, E & F- 'The man and the dragon' and the symbolic drawings

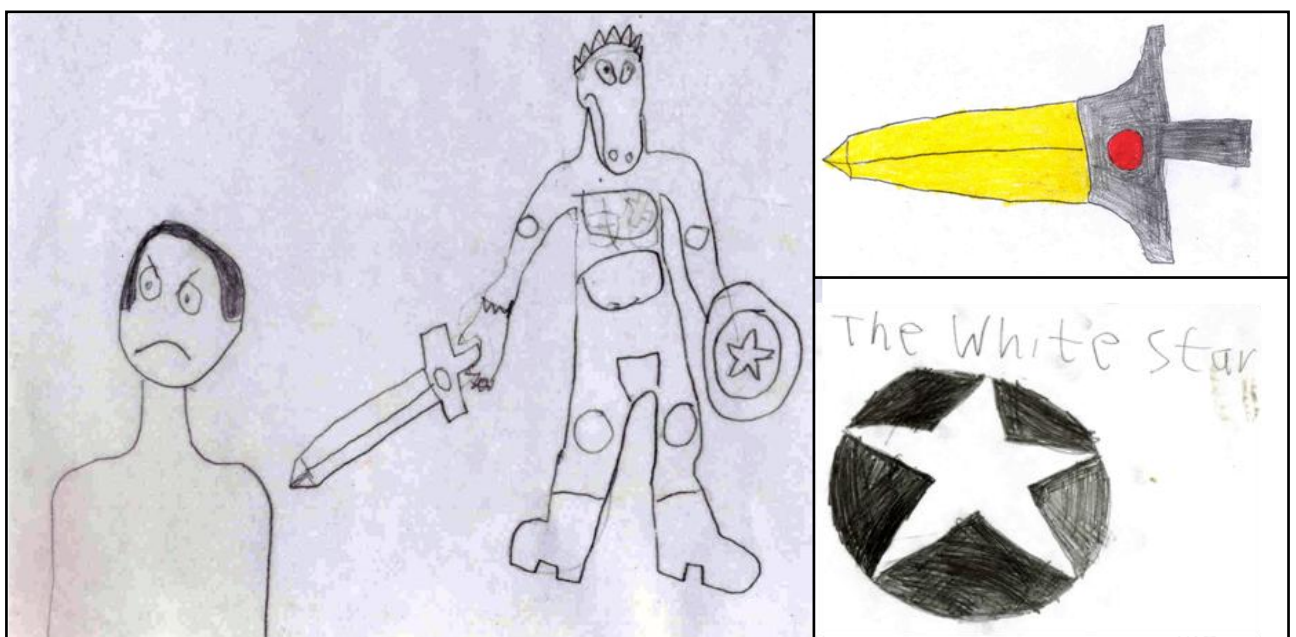
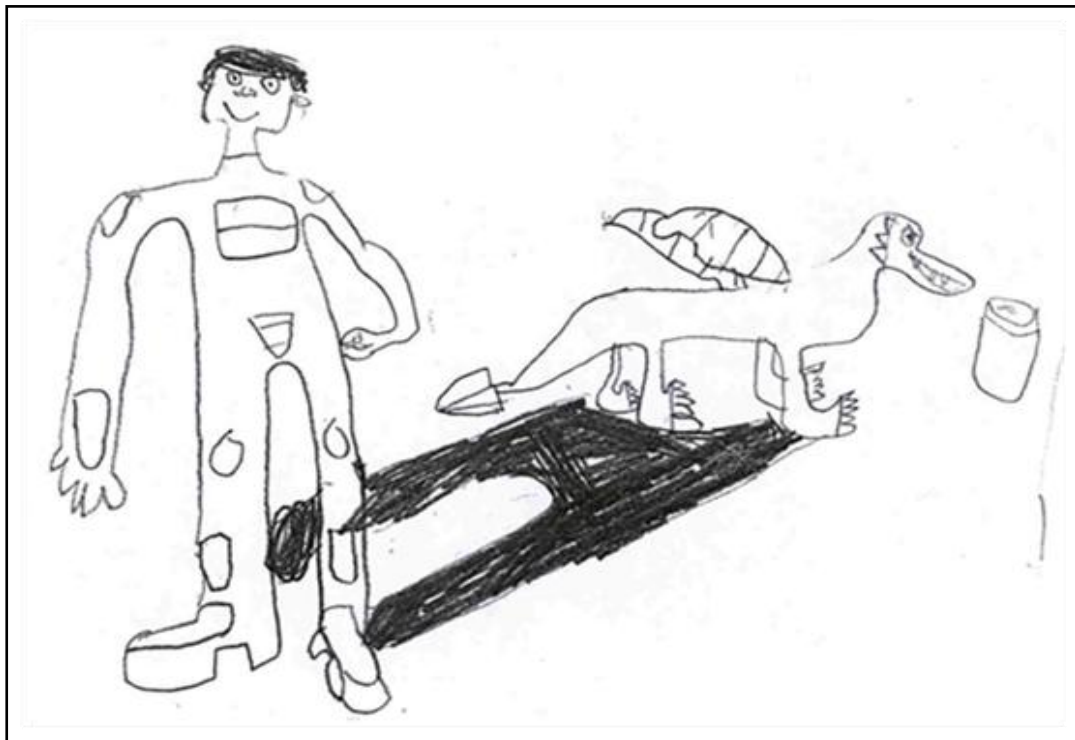


Figure D (18/03/2009) is a depiction of the separation of man and dragon. Here Aron has taken on the persona of the dragon; he has departed entirely from his human form. His human body is a lifeless shell waiting to be re-inhabited when Aron the dragon returns from battle. Aron the dragon is armed with the symbolic ‘Soul’ sword that appeared very frequently in Sean’s single symbolic drawings, and Aron’s sword carries the symbol of the ‘White Star’ which also frequently appeared in Sean’s symbolic drawings (figures E- 26/03/2009 & F- 10/11/2009).

Figure G (04/02/2009) is a remarkable drawing in my view. It is a direct depiction of the good and evil sides of Aron. This is the only existing drawing of Aron in which he is smiling. This is because, in this drawing, he has completely freed himself from the dragon and has achieved a purely human form. In this drawing the dragon is not portrayed as a fighting hero- it is no longer standing in semi-human form. The dragon is portrayed instead as being menacing and evil. This drawing essentially represents Sean’s rejection of evil. While all of Sean’s other drawings of Aron portray him as a sort of reluctant hero in an internal battle with himself; bring driven to fight evil but at the cost of becoming evil, this drawing suggests that Aron (and by association, Sean) is ultimately happier in rejecting evil entirely, and fully assuming the role of the “good guy”.

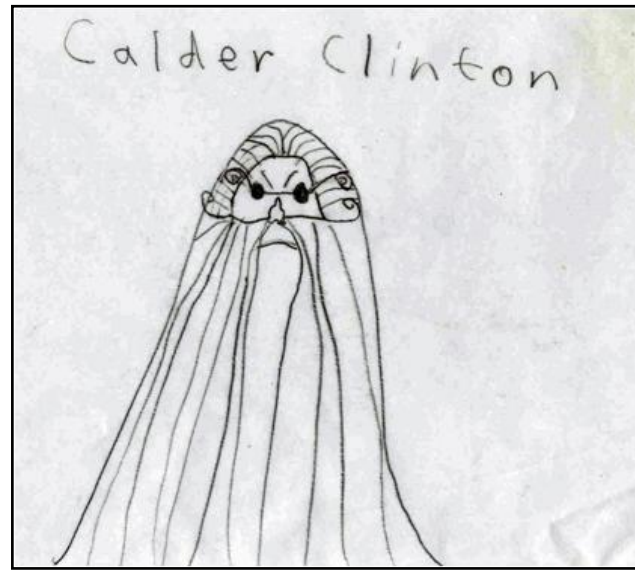
Figure G- The separation of man and dragon



An investigation into the nature of good versus evil- on the level of individual characters- heavily underpinned Sean’s ‘Disaster Game’. Yet to investigate whether or not people can be both good and evil, Sean had to first figure out for himself if people (as investigated through characters) can be *more than one thing*. A classical feature of autism, as discussed, is the tendency to separate and systemise everything. Merging items of information and recognising that things, and people, are multi-dimensional; having more than one function, and more than one aspect- is an extremely difficult thing for many individuals for autism to learn. Yet, in my

experience, (Sean being only one example) people with autism are naturally driven to explore this phenomenon in their own way which is often revealed in their artwork. I have collected hundreds of drawings created by my pupils which depict hybrid characters. Figure H, a drawing created by Sean (02/09/2010) is a classic example of this. In this picture, Sean- who is very interested in the American presidents- merged President Bill Clinton with the character of Calder from a video game creating the character of 'Calder Clinton' who Sean said "wants to be the next President of the United States, just like his father before him."

Figure H- 'Calder Clinton'



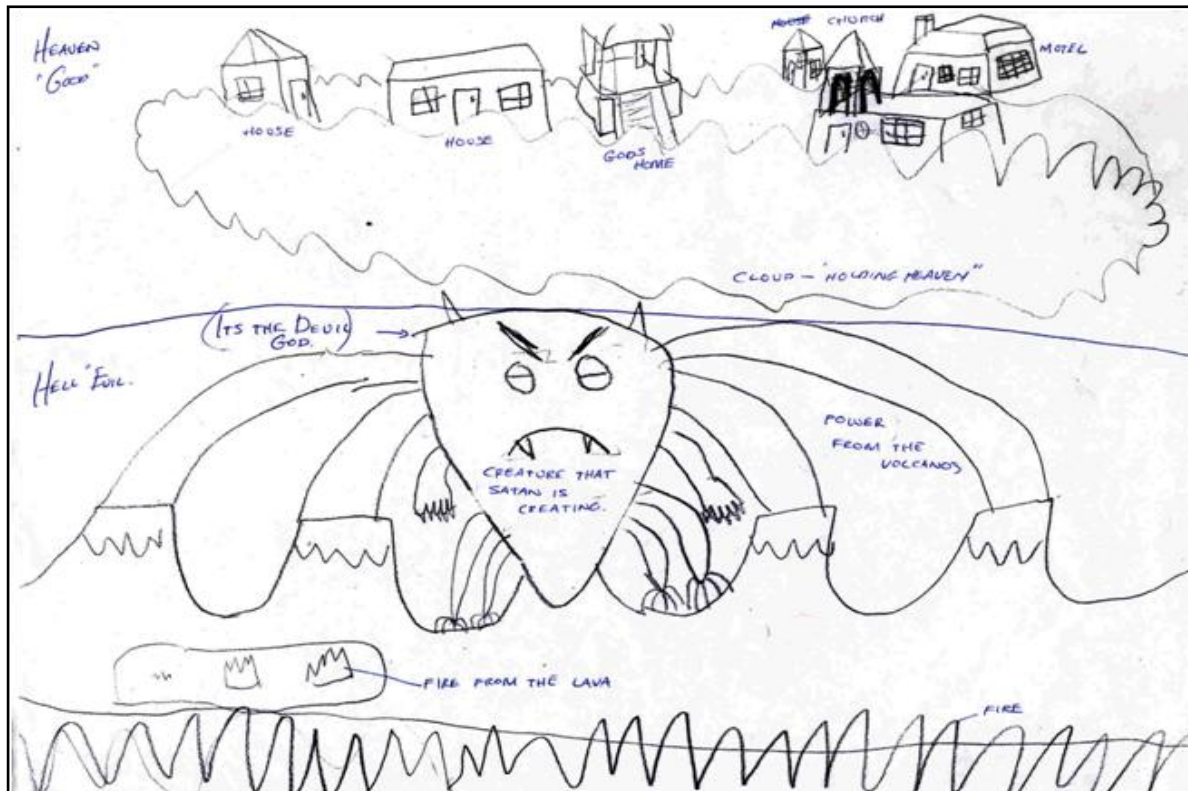
Having learned that characters can be composed of a dichotomy of sorts, Sean went on to investigate how this dichotomy may play itself out when aspects of self are in conflict with one another. An analysis of his spontaneous written dialogues reveals how this investigation took place. Dialogue A (20/03/2009), for instance, features the characters of 'Batman' and 'Sonic the Hedgehog', both of which Sean prescribed a 'good side' and a 'bad side'- 'Batman' & 'Dark Batman', and 'Sonic' & 'Dark Sonic'.

Dialogue A- Batman versus Sonic the Hedgehog

Dark Batman: Stop right there! ^{20/03/09}
You will never get those gloves!
Sonic: Evil Batman, we will defeat you.
Dark Sonic: So you're the real deal. huh? Would you like a race?
Sonic: are you making fun of me?
I Guess I'm ^{not} smart after all.
Dark Sonic: I Guess that's your last words. Time to die!

This short dialogue was written as a 'stand alone' piece. It was not part of 'Disaster Game' within which the dichotomy of human nature was explored in spectacular depth. Perhaps the drawing that best contextualises 'Disaster Game' is figure I which Sean created on February 4th 2009.⁶⁰

Figure I- The context of 'Disaster Game'



'Disaster Game' was ultimately a battle between good and evil, 'good' through the projection of God, and evil through the projection of the Devil/Satan. 'Disaster Game' was set within the context of the Devil's attempts to corrupt earth. Satan creates the 'Devil God' who rising from the flames of Hell sets out to corrupt earth. Figure J (22/01/2010) portrays the 'Devil God' once he has escaped from the fires of Hell.

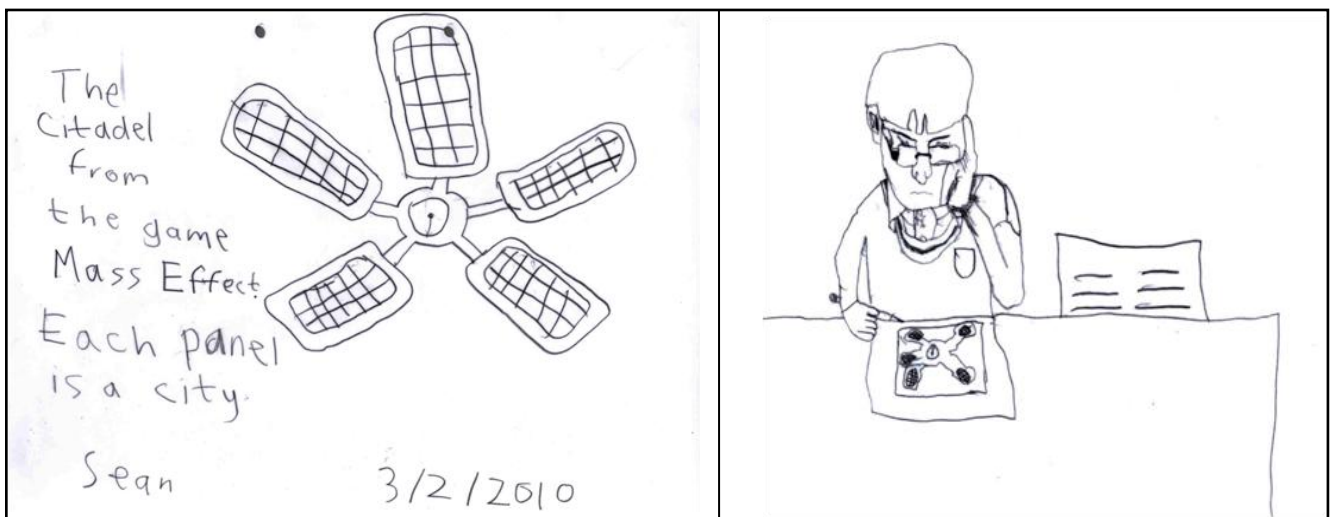
⁶⁰ The labels which appear on the drawing were written in by me as Sean (unexpectedly) explained the picture to me.

Figure J- 'The Devil God'



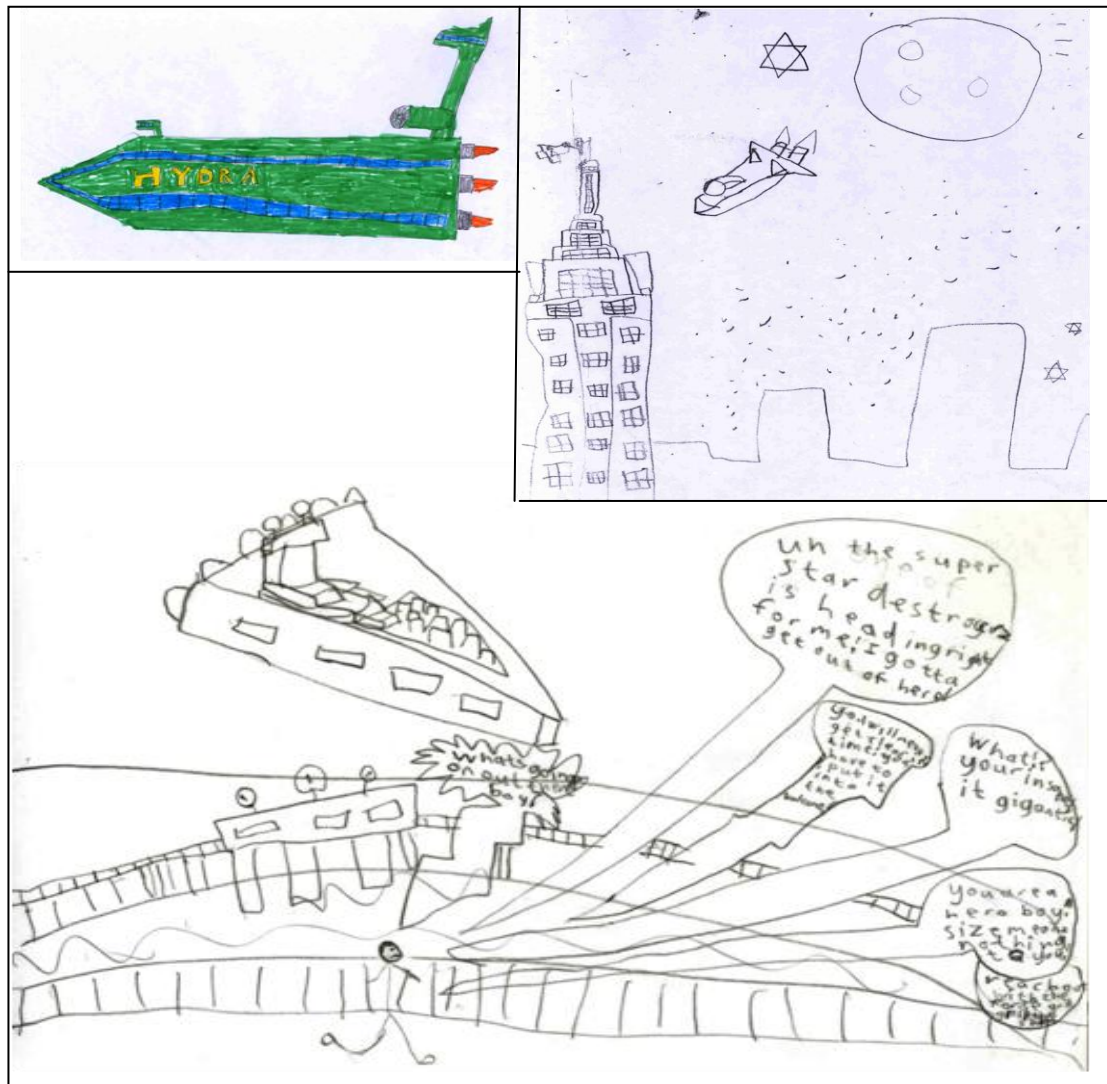
The protector of earth is Aron, chosen by God to defend mankind from corruption. The scenes and battles that took place in 'Disaster Game' conformed to the levels that one would commonly find in video games, in much the same way that, as illustrated by Sean in figure K, in the video game 'Mass Effect' each panel from the citadel represents an individual city. (Figure L is a portrait of Sean drawing the citadel, drawn by his classmate Gary Prendergast)

Figures K & L- Drawing the Citadel from 'Mass Effect'



Aron's vehicle of choice is a space ship named 'Hydra' (figure M) upon which Aron travels between these levels and universes. The action sequences in 'Disaster Game' usually took the form of invasions coming from enemy spaceships. Figure N shows one such invasion set around the Eiffel Tower in Paris while figure O shows Aron's spaceship under attack from the 'Super Star Destroyers'.

Figures M, N & O- 'Hydra', the invasion of the Eiffel Tower and the attack upon Aron



A central character in 'Disaster Game' was the 'Devil's Daughter' who Sean called 'Ciara'. The interplay between Aron and Ciara was, I believe, of enormous significance in Sean's investigation into good versus evil and the dichotomy of personality. In dialogue B (30/03/2009) Aron transforms into 'Dark Aron' revealing the evil side of his personality as he threatens to attack Ciara in her human form.

Dialogue B- 'Dark Aron'

Ciara: you will pay for what you did to me!
Aron: No! Ciara! (the darkness spreads on Aron)
Ciara: What?!
Aron: aahhhhhh!!!
Ciara: No! No! No! No! No!
Aron turning to Dark Aron: Ciara!
Get ready for a world of pain!

The opposite type of scenario plays itself out in dialogue C (23/03/2009) when Ciara in her non-human form (the 'Devil's Daughter') plans to kill Aron in the form of the 'White Dragon' before he is dramatically rescued by 'Sonic the Hedgehog'.

Dialogue C- 'Dark Ciara'

1
Aron: wooh! what did you do that for?
thats not nice!
Devils Daughter: you must ^{be} that
white Dragon.
Aron: do you know who I am? I am a Man!
not a Dragon!
Devils Daughter: Hahahaha! I am Ciara,
The Devils Daughter! I came to kill you!
Aron: wait! I'm ^{not} looking for a fight!
I'm just looking for a sword!

Dialogue C continued

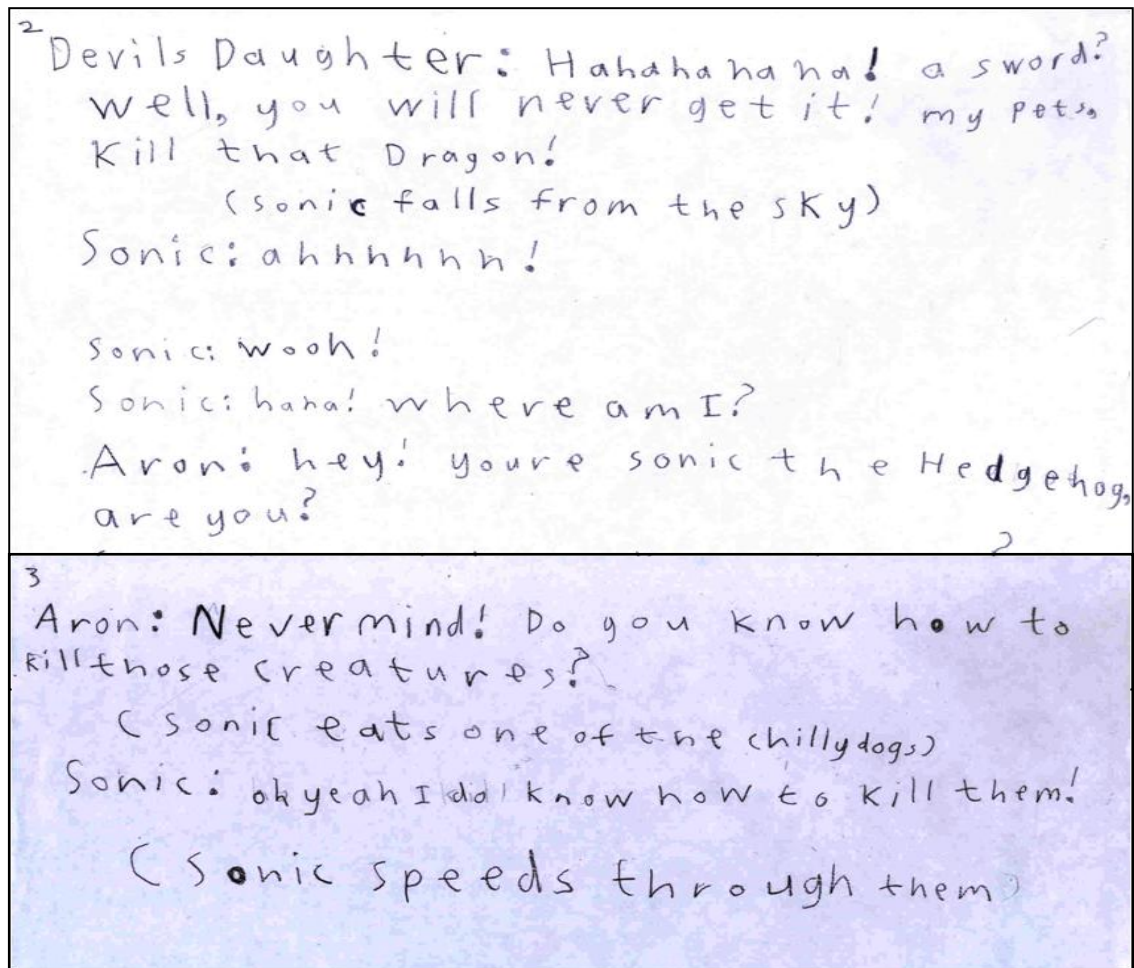
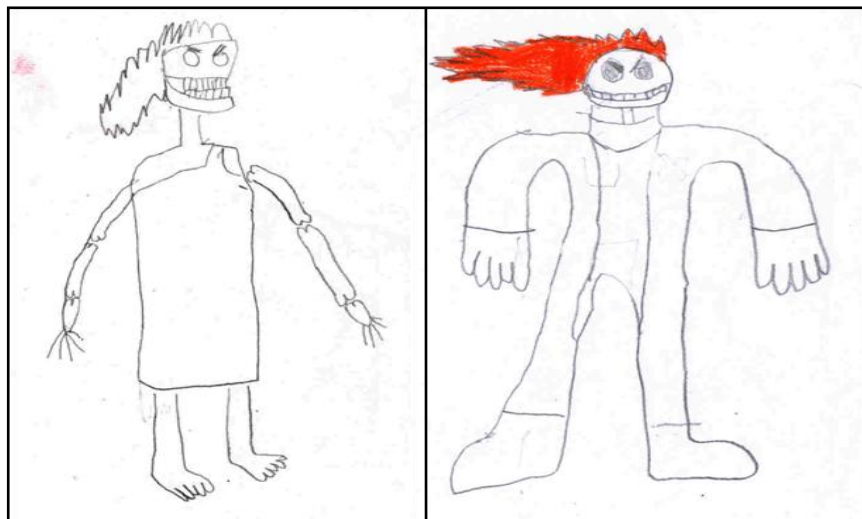


Figure P (18/03/2009) depicts Ciara as the 'Devil's Daughter' while figure Q (18/03/2009) depicts her in her human form.

Figures P & Q- The good and evil sides of Ciara



Before the 'last level' of 'Disaster Game', Aron visited heaven where he met God and 'Thor', the God of Thunder. Here he is given the final challenge- to save the universe by acquiring the 2 'Soul swords', as described in dialogue D.

Dialogue D- When Aron meets God

Aron: am I dead? why does Heaven smell like fire? Oh wait, never mind.

Shadow: Hmm!

God: I am God, The father of Jesus. you are needed to save all of your worlds. Listen carefully. The Devil has become The God of Evil. I have TransPorted you to Heaven, so that I can give you a chance in saving your universe.

Thor: Who can stand a chance against the Devil? even we can't defeat him!

Aron: We know hes to Powerful. but you must know a way to stop him.

God: yes. theres a chance. but it will be difficult. first you must obtain the 2 soul swords: Soul Calibur and Soul Edge.

In the 'final battle' between good and evil, Aron defeated Satan, returning the "Devil's earth"- "the earth corrupted by the Devil"- (figure R) to its former uncorrupted state (figure S), a process through which Ciara was transformed from the 'Devil's Daughter' into a 'beautiful woman' for all eternity.

Figures R & S- The corrupted and uncorrupted worlds



APPENDIX H- Interview with Mr. Brendan Cronin, member of Royal Cork Yachting Club (14/06/2010)

Steve: Brendan, thanks so much for bringing us out.

Brendan: It was our pleasure.

Steve: Brendan, do you think that Sean enjoyed this activity?

Brendan: Well I certainly got the feeling he enjoyed it. His responses were very good, very excited, I think the whole experience of the sea was there, he was asking lots of questions, he wanted to know about the instruments, how they operated, how they functioned, how everything worked. Ah, he was a bit anxious if we were going out to the open sea or not, was happy enough once he was in the confines of the harbour I felt. He got a little uneasy if he thought we were heading out to sea- the great unknown- but within the confines of the harbour he was very happy, very excited by the whole thing I felt.

Steve: The next question, which you've really already answered is was it what he said or the way he acted that gave you these impressions?

Brendan: I got lots of questions, you could see the animation, he was quite excited and animated which was an indicator obviously, a bit apprehensive as you'd expect being out in the water but got used to it and asked lots of questions which is a good indication that there was interest there.

Steve: I was impressed by the fact that he could manage the steering. He does love boats. What supports would need to be in place if we were to try to develop this into a life long hobby for him? To do this on a weekly basis, what sort of educational options would be there for him?

Brendan: Well a motorboat of that size isn't the best medium to start with, that would challenge anybody who is not used to it. There is a big learning curve for that. A small boat yes, definitely I think, but anything with power would, I suggest, need to be under supervision. But with supervision, constant coaching and practice, I'd say he wouldn't have a problem. A smaller boat and lower powered. Supervision would be required, somebody accompanying him, put them in charge in an area where there is a lot of other activity around, is not so much being competent at what you do yourself, other people do stupid things, people coming across you in dingies and stuff like that unexpectedly, they are the situations and circumstances you'd worry about and with power there's always a risk and danger you know, so from that point of view- supervision, lower power and a smaller boat definitely. But for boating activities in general, I'd say a small dingy or a rowing boat or something like that with a paddle and things or a sail boat, here at royal Cork we do a lot of sailboat activities for people with special needs. It's very well developed in terms of coaching and training and being patient and understanding of the fact that people's responses will not be as easy as you'd normally expect with a person who does not have special needs.

Steve: The one thing that I think that he does love is the power side of things. I think the fact that he just had the experience of putting his hand on the throttle and giving him the feeling of power was huge. It is a very rare occurrence for him to be that animated, to be asking all those questions. He immediately took to you and I think that the reason for that is that your

doing something with him that he wants to do. I also think the rocking motion really woke him up.

Brendan: To support what you said actually, what I noticed was that when we got into a little bit of rough water he got quite excited with the wave motion, he said 'this is kinda good' and when we got into calm water he got a bit bored. Now that you mention it I did actually notice that. When we got the speed up he started going with the motion of the boat, rocking with it and enjoying it. When it was calm out there outside Roaches point then suddenly he was getting bored.

Steve: Bren, when you heard that you would be working with a teenage boy with autism what were your initial thoughts? Like when you rang me earlier?

Brendan: Well my understanding of autism, first of all I did understand and appreciate that there was a huge variation in levels and my impression was that he would have no interest in communicating with me, as such and so therefore the reason I rang you was that should I bother even trying to attempt to communicate or should I just leave him alone? My understanding was that with autism you give very clear instructions, you just leave it at that. Clear instructions, nothing confusing. That there is not an intelligence issue here at all, of that I understood, but beyond that the level I was facing was something that I didn't know, whether I should attempt to actually say hello and introduce myself or not, or simply ignore that and give instructions, so I just wanted clearance on that and you handled that very well. Once you introduced him to me I knew straight away he was into conversation.

Steve: Finally Bren, could I ask if you have ever met or had any social experience with any other person with autism prior to this experience?

Brendan: I do know one other kid that we meet down in west Cork, Philip. He is much younger than Sean. He's about ten. He can communicate but he wouldn't actively seek to engage with you at all. He could walk into a house and just sort of look around, walk up and down, check everything out, and walk out the door again. He wouldn't say a word to you really.

Steve: This final question has been answered really already; do you think that Sean was inclined to communicate with you directly throughout the course of this activity?

Brendan: Yes. Definitely. To a level that I wouldn't expect.

Steve: Is there anything else that you would like to comment on generally?

Brendan: I suppose the only thing you'd feel about the chap is that is there a level beyond which he can ever get? You know that's the sad part about it I suppose. You know, what's the objective? I'm sorry I'm asking the interview questions now.

Steve: No, please do. That's fine. This is supposed to develop into a conversation really.

Brendan: If the objective is to get to the maximum performance levels out of Sean, and then if that doesn't cause stimulation, does he go back from that, does he regress?

Steve: Well its not about trying to push him to get to as high a level as possible and turn him into a professional sailor, and maybe my questions were misleading in that, although he does love the water and this could be a serious move in a direction, its not that he needs to be able to run power boats on his own but that he can enjoy the experience.

Brendan: Yes!

Steve: Well Bren that's pretty much it. Finally, would you mind if I used your name in the write up of my thesis?

Brendan: Absolutely.

Steve: Thanks Bren.

Brendan: Thanks Steve.

**APPENDIX I- Interview with Ms. Joanne Lenihen, life guard & disability officer
(16/06/2010)**

Steve: Joanne, do you think that Sean enjoys swimming here? Do you think he looks like he is enjoying himself?

Joanne: Ya, he's laughing away to himself, jumping up and down, he seems quite happy to be here. There's no complaining or moaning, he's just enjoying the activity.

Steve: Would you have any concerns in relation to his safety? Do you think he can be fully independent in the water?

Joanne: Well he's tall and can stand in the deep end. I didn't see him swimming so I don't know what his swimming ability is like. But as for enjoying himself in the water, he seems to be fine.

Steve: Would you have noticed anything unusual about his behaviour?

Joanne: Well he doesn't swim a lot but he likes to stand on the boards and balances on them a lot, they help to keep him focused.

Steve: Would you be able to recommend any other activities that he might take to in the water because he does love the water?

Joanne: Outside of the mainstream we have instructors who work with people individually. We do confidence games to get them used to the water. We do kangaroo jumps, get them to lie on their back. There's a range of activities and educational games.

Steve: Would he be a bit old for some of those activities?

Joanne: No well for example instead of a kangaroo jump we could do a squat jump. You can adapt it and make it far more adult.

Steve: I think we might try that. Who would I go to in terms of getting that sorted out?

Joanne: You can come to me.

Steve: What would have been your overall impression of Sean having observed him today?

Joanne: Well we know him from coming in. We know he's autistic. But if you didn't know that you might just think that he's a very quiet child playing. I would say that he looks quite normal.

Steve: I've noticed that ye cater for a lot of people with special needs here.

Joanne: Yeah, well I'm the disability officer. I have people with special needs coming in all the time for swimming lessons, people with Cerebral Palsy, Down's Syndrome and other disabilities. We have people with various disabilities who do mainstream lessons as well.

Steve: Whenever I do any lecturing for the COPE foundation, I always mention that the level of inclusiveness here is outstanding.

Joanne: We are always trying to promote that. We always say come in and we do what we can to help. A lot of people say that they can't get swimming lessons for people with

disabilities. They say there is no one doing them or certain clubs don't want to take them on. So we do the 'Halleyway', the one to one, and we also mix the 'Halleyway' with the mainstream depending on their ability. The gym has also become more disability friendly now as well and there are more people with disabilities coming into it, using the cross trainers and the treadmills and stuff.

Steve: I will organise a session with yourself and himself. Would you be happy to do a follow up interview with me after that?

Joanne: Not at all.

Steve: Would you mind if I used your name in my thesis?

Joanne: No problem.

Steve: Thanks Joanne

APPENDIX J- Interview with Mr. Jason Carey, horse riding instructor (17/06/2010)

Steve: Jason, how long has Sean been coming down to you here to do horse riding?

Jason: I've had him now ten or eleven times and it's been for a half an hour each time.

Steve: How do you reckon he's coming on? Do you think that he likes it?

Jason: He's grand ya. But I think he finds it hard to focus and if he had the focus he'd have the ability no bother. But it is just trying to get him to focus. He's got a lot of things rabbiting around in his head. What was his last fixation? It was the earth flipping and the whole lot in 2012. He was fierce upset and worried asking will the horses be OK and what's going to happen.

Steve: Ya, we sorted that out in school and I think he's OK now. What I was noticing with Sean on the horse is when there is a lot of motion involved he seems to become much more alert. Would you have found that with him?

Jason: He would do, ya, and I've seen it in a few others as well you know as soon as they sit up. Like there was a girl who used come here before. She wouldn't talk to you, sit her on the horse and next thing the language is perfect, and for a couple of hours afterwards she's as right as rain, and then she starts to drift back in again you know. He kind of exhibits that alright. But he's coming along you know, a bit more time and if I can give him something to focus on. It's just trying to hold his attention is the main part.

Steve: Do you mind if I quote you in my thesis?

Jason: Ya, no bother. You should also talk to a person called Joanne Fletcher in the College of Commerce who has done a thesis on animal therapy.

Steve: I will Jason, thanks.

APPENDIX K- Interview with Mr. Gavin Daly, motorsport instructor (07/07/2010)

Steve: Gavin, you mentioned that you get a good few people with autism coming down here. Could you tell me a bit more about that?

Gavin: Ya, like I'm working here a good while now and with my first experience of autistic people coming up, I didn't know what to expect to be honest but I've had not a problem with any of them at all like, they're all actually perfect like, not a problem at all, they're better than most normal kids who come up here, they're actually perfect like."

Steve: I was initially afraid to leave him off on his own the next thing I know.

Gavin: A lot of people think that alright but they're actually perfect like.

Steve: Thanks a million Gavin. Would you mind if I used your name and quoted you in my thesis?

Gavin: No problem.

APPENDIX L- Interview with Corin Morgan Armstrong- Tae Kwon Do Instructor
(24/07/2010)

Steve: Corin, could you generally reflect on what your perceptions were both before and after you did the Tae Kwon Do session with Sean on Friday?

Corin: My perception would have been based upon what my planned approach was. My planned approach was to be pretty flexible and a number of different activities in my head that I would order in terms of his responsiveness and ability. So I guess my before perception was probably fairly low in terms of what he'll be able to do, his attention span and his interest. My own personal goal was to get him to do the best part of sixty minutes. I wanted to see if I could engage and work with the guy for as much of the hour as possible. So I suppose going into it my perception of what his ability would be and his interest, I kind of set that quite low.

Steve: Could you run through the areas that you covered with him, as I am completely unfamiliar with the sport of Tae Kwon Do?

Corin: OK, well we started off just with a bit of a warm up. During that warm up I was just keeping an eye on him and just seeing physically what he seemed capable of and whether he had any kind of aches or pains or any physical limitations, he seemed OK there, and then after that I thought I would try to teach him a very basic pattern which is basically in Tae Kwon Do a set of movements that start off very basic, they're in a fixed sequence and they have a symbolic significance to the art itself, any I tried to do that with him to see how that went, and then I also brought a pad along cause I wanted to see him kicking and see what his coordination and ability was like there. Similarly with punching on the pad, then there was some stretching to see what his flexibility was like. Then also we did some reaction speed tests in terms of his ability to be able to do basic, low speed blocking around his head and then blocking kicks to the thigh. We finished off with doing some stuff on the punch bag just to see what he was like with his elbow and his knee and hitting something which had some resistance. That was essentially what we did.

Steve: Which areas do you think he performed best in?

Corin: He didn't...with the pattern that we started off with...he didn't..I think perhaps if I had done that toward the end rather than at the beginning he probably might have been able to grasp more of it. But I mean it's a hard thing to do, even with completely able bodied and minded kids of his age, to learn that pattern in your first ever hour of Tae Kwon Do would be very difficult, you know, you would find it difficult, any adult would find it difficult, and you're not likely to grasp it in an hour but you might grasp the basic template of it, the kind of physicality of it. So you know, he was OK at that but I don't think it particularly interested him. It was probably a step too far for him. I think what he showed a better aptitude towards was kicking the pad. His legs were quite strong and he put some power behind his kicks and some focus, some aptitude. When we were doing the same exercised but with punches he didn't seem to grasp that. It was like he didn't like it. There didn't seem to be any power in his arms even though he's quite big for his age, there didn't seem to any real strength in his arms. He found it difficult to keep his fists clenched. He'd clench them and then he'd kind of forget. He'd unclench them and then he'd hit the pad with a kind of half clenched fist quite feebly. So that wasn't great.

Steve: How about his coordination?

Corin: His coordination was good. I think what he was best at was the reaction tests. You know, I said I'm going to try to flick your ear with my finger, standing about a foot away from each other, and then just showed him basically how to stop me doing that by raising his hand and blocking me in a very simple manner. He was good at that, he had good reaction speed, good coordination and good focus as well. And he enjoyed it as well. I think that's what he enjoyed the most. He was smiling and he seemed to quite like it. He liked the challenge of it, it was like a little game and he seemed to get into that. And he was good at it. He was coordinated more so than I would say probably people, be they children or adults or teenagers in their first session of Tae Kwon Do. He has a better reaction speed than most people in their first lesson.

Steve: With Sean, the first time that he does anything, even if it's something that he quite likes, he keeps asking how much time is left as he did on Friday. Did you find that frustrating or discouraging as Sean's instructor?

Corin: No personally, I think it's very, very common really I mean teaching children, whether they're somewhere on the autistic spectrum or not. It's pretty much all the same. Children need, especially learning a martial art which is quite a complex thing for anyone- and particularly a child or teenager- to grasp what is physically that is being asked of them. With a martial art it's not just the physical aspects, it's about mental aptitude, there are aspects of spirituality, philosophy, history, and it's a lot to grasp and people do it as a life time and still you'll never grasp it all, you know it's one of those things. I would find it very common teaching children- they know the parameters of time- it's usually about an hour, sometimes an hour and a half, but they know that if they get dropped of at six o'clock, when the big hand gets to seven the sessions over and they can see the clock through the session. And I'm exactly the same. You know, I've been training twenty four years and sometimes my motivation when 'm training is very low, and I don't particularly want to go, so I'm looking at the clock during the session as well and if I'm not particularly motivated in a session I'm thinking kind of 'are we there yet?'. You know, so that's completely normal and what I found with Sean was that he got into a thing asking how much time was left etc etc, but what I found was once I pointed out the clock to him and said when it gets to one o'clock the sessions over, after that point he didn't really need to ask me about that anymore cause every now and then he'd glance over at the clock and he could see for himself. And once he knew that he concentration went up and he was easier to engage and his motivation went up as well. He knew there was a finite amount of time, it had a parameter on it and when it got to that point he'd be doing something else. And I think that's the same for anyone.

Steve: Leaving Tae Kwon Do aside for a few minutes, could you reflect upon what struck you about him or what you learned about him particularly on the drive to the gym.

Corin: Well he clearly has a good memory and has a head for facts and figures, countries, historical military leaders that we were talking about. He has an interest in the world wars and we also talked about big bang theory, dinosaurs and Ice Age and all sorts came up. He's clearly interested and has gone out of his way to find out about these things that interest him and he has retained that knowledge and he can reflect that knowledge back to you in a conversation in quite an adult way I thought for his age you know regardless of the fact that he is autistic.

Steve: Have you had any previous experience working with any individuals on the autistic spectrum, and if so could you compare those experiences with your experience working with Sean?

Corin: I've taught a couple of autistic children over the years. One of them was in a very small class that I was running, there was only about five people and it was a couple of kids and their mums basically. He was quite difficult because he really struggled to stay focused and engaged and his attention would wander very quickly. He became frustrated when he couldn't do things and that then limited his ability and he didn't stick with it. He was probably about seven or eight years old. Then more recently over the last couple of years I've trained with and taught with a guy who, he's twenty one, and I don't know the detail of it but from speaking to his mother he has quite severe autism and some other additional complications along with that. Although he's twenty one he comes across more as a fourteen or fifteen year old. He's a huge guy, a massive physical bloke, and quite brewing and quiet but once he feels comfortable and confident with someone he's happy to approach them and talk to them. I know through his mother that since he's been doing Tae Kwon Do she said that it's completely changed him. He wouldn't leave the house before. He was so worried and anxious about going outside, not about being attacked or anything, but the whole social aspect of being outside of the house and away from his mother was just too anxious for him, you know he couldn't do it. But through doing Tae Kwon Do I guess his confidence has gone up and he holds down a job in Asda you know and I see him out and about the town on his own and he's got a small circle of friends and he seems like any other guy. Even though he's twenty one he would come across more like an eighteen or nineteen year old now than how he was before. And in terms of his Tae Kwon Do he is not dissimilar to the experience with Sean really. I mean he finds aspects of it very interesting and kind of concentrates on those, and the other bits- the bits that don't tickle his fancy- he's a bit lazy with, but he kind of picks and chooses. And that's fine, I think we all do that to a degree but I guess he's just a bit more obvious about what he does like and what he doesn't like. When he's training he's very coordinated, very, very strong guy, it's like being kicked by a tree trunk, he's a massive bloke. Clearly it's had a really powerful benefit to his life and the life of his mother as well.

Steve: The point of doing these activities is one level to find out the activities that he likes and doesn't like but from that I am trying to find out what would need to be done in order to continue the activity on in his life. Assuming the support, good will and finance is there what would realistically need to be done to get him to a level where he would be able to continue the activity on through his teenage years?

Corin: Not a great deal really. I think what it would probably come down to is the person who was teaching him and the club that he was in. The instructor who I'm affiliated with and his clubs, he has over five hundred students across South Wales, it's a massive club, he's very open minded, and over the years he's taken you know all kinds of kids with different...you know kids with criminal records, kids who are in trouble with the police, kids who are dabbling in drugs, kids who are like violent at school, autistic kids, kids with Aspergers, you know all sorts of different problems, you know kids with like paranoia and all sorts of anxiety complexes, he would take any of them, and that's not because he's greedy and he wants the money- because he doesn't need it, you know he's got an enormous club- himself and his wife who also teaches, they have a very laid back attitude, a very nurturing approach to working with these kids, and because they've seen, as I have over the years, is that Tea Kwon Do can be- not all the time and not with everyone- but it can be transformative, particularly with kids with different issues whether their medical or

psychological or emotional or whatever- it can be transformative- and it can be a catalyst to huge change and you know that's why they continue to do it. I guess in answer to the question it would be, like if he was in Bridgend for example, having seen what I saw of him yesterday, if he wanted to continue doing it- and it would have to come from him- then he would be welcome in the club that I'm in with my instructor and he would fit in, and it's not a case of saying that he wouldn't get any special treatment because ultimately he would because people need to know and they need to understand it, but if you've got that, if that's in place, if the understanding's in place, then I think really you've got a nurturing environment where he feels safe and he's encouraged and the people working with him understand his limitations, but also how to motivate him and progress him, I think that's all you need really. Steve: And do you think, say if you were teaching a group of twenty, do you think that he would need to have somebody with him one to one?

Corin: Yeah, I think so. In comparison to other kids with autism I've seen he would be I guess more extreme in terms of when he goes into himself, that's more extreme than I've experienced with other kids, and what I've seen with the other kids is that there's always a carer or person with them. So with the big guy, his mum does Tae Kwon Do too, not all the time, she used to do it all the time and now she does about one in five lessons that he does but that's because he's grown in his confidence and he's happy with that. But certainly with Sean he would need a carer or somebody with him you know in order to be able to deal with incidences where for whatever reason he does kind of disappear into his own world for a bit. Then over a period of time that might change. He might feel confident enough not to feel the need to go into his own little world and so that negates the need for a carer to be there as much as much as they would at the beginning.

APPENDIX M- Interview with Pat Falvey- professional mountaineer (28/07/2010)

Steve: Pat, today Sean endured more physical strain than he has ever experienced in his life. There were times that I felt sure that he would want to give up but he didn't. And that really brings me to my first question; what do you think it was that kept him motivated today?

Pat: From my point of view and experience in relation to mentoring, and in relation to education- in people having goals and ambitions, what Sean had without a shadow of a doubt was a goal. His goal was multi purposed and I totally and honestly believe that anyone who has goals and dreams in life, that they will do anything to actually achieve them.

So what I found with Sean today is his goal was basically to raise money for children in Russia. And this was his motivating factor and he used the fact of making himself a challenge, the likes of Carrauntoohil, that he was going to get to the summit of it. And when he took that challenge, which amazed me like for an autistic child, that he took that goal and focused on it. And how I know that is that every time that he stopped, and you know of course that I threw it to him, and he was very, very alert at the fact "OK so Sean, we'll go down." Straight away he rebounded back and he said "No, we won't go down, we go up."

So no matter how tired he was he was completely and utterly focused on the goal. Now the first goal of course was to raise the money for the children, the next one he had to get to the top of Carrauntoohil. The third one he had, and throughout the whole period of time no matter how exhausted he was, was that he didn't want to disappoint the people that gave the money. So he had a number of goals and all the time processing in his head was the fact that he had to achieve one thing, two things, three things for them all to come true.

He was completely and utterly driven, every time we said we'd go down the answer was no. So then we had to set about giving him another focus. This was the fact that he had to get to the summit by three o'clock (to ensure a safe descent). So overall what I have found was that by stimulating Sean in particular, and we've dealt a lot with autistic children in the past- we've raised money for them and things like that- is that with a lot of the children that I see the aspect of challenge is taken away from them because the bureaucracy in a lot of instances say that these children are not capable of deciphering challenge, but without a shadow of a doubt what I have seen today goes to prove that by stimulating challenge and goals, it stimulates their endorphin to achieve and more so than ever today.

You know I have worked a lot with special children and things like that, we could see in Sean that he was totally and utterly driven by his goals. And he knew what his goals were, they were very focused, very clear, and to him getting to the top of Carrauntoohil was in itself an Everest. So from that point of view it was amazing, you know cause I met Sean a couple of times and he's a very forthright young fella, but what amazed me you know without a shadow of a doubt was his ability to retain focus on goals. And why? You know of course there's lots of different autisms, and I understand that, but with Sean without a shadow of a doubt, if you can stimulate him with goals he'll go out and he'll actually achieve whatever it is he wants to do.

Steve: You've pretty much answered all my questions there, which is great cause this is supposed to be an unstructured interview in any case. If you were to consider what you thought this morning or yesterday to what you think now, I mean would you have had worries yourself in terms of what could happen?

Pat: Look its dangerous, without a shadow of a doubt. Anyone who would say that Sean was going to go up Carrauntoohil would have said it was mad because of the dangers involved. Of course for myself to take the responsibility, and Joe, of course it is a great challenge but knowing the fact that someone has a dream or goal in life you know doesn't mean that they have to be restricted and that's the reason why we took that goal on.

Was it dangerous? Of course it was dangerous. Could something have happened? Of course something could have happened. Would we have allowed something to happen? We were very, very cautious. In other words when it got into the steep ground we put Sean on a tether, you know that he was held between Joe and myself. But in saying that there's no reason to restrict people from fulfilling their dreams. Will Sean remember what he's done today? I just don't know. When I met him you know and we were going up was I concerned? Of course I was. Did I actually set objectives? Of course I did. Did Sean understand them, which was more to the point, he did.

He understood he had to be at the summit for three o'clock. If he was ten minutes away from the summit by then he was assured we were going to have to turn. So he was actually in his mind all the time, he was looking at the watch, he was processing the time that he had to do it and when he sat down the way we got him motivated again was by saying well look Sean you're not going to meet your objective. And he was completely, utterly focused on the fact of achieving his goals within the times that were set for him.

You know, in other words when we said sit down, we said two minutes, we gave him the responsibility of saying lets go, he watched the watch and he said "let's go". When it came like to six minutes past two and I said it was six minutes past two he looked at the watch, and the minute the watch hit six minutes past two he said "get up". And I think you got some good video that will actually go to show that when we did actually recommend he go down, which was just a stimulant to get him going to see what way he'd respond, he responded positively every single time to the fact that I'm getting up, I'm going, I'm going to get there and I'm going to get there on time.

And of course yes the big fear was going up or coming down but, like you know, that's my profession, I'm a professional mountaineer, and you know, mountaineering is dangerous, but in saying that we have the ability to make it safe- to a degree- but there's no way that anyone could have forecast that everything would have gone according to plan. We had to make it go according to plan.

Steve: What struck me was that when myself and Joe did the prelim training on a mountain in Gungan Barra, the problem was that he tended to rely on Joe for everything, especially when he was on a rope, but I think what happened today was that he started taking more responsibility for himself. O.K every once in a while he slumped a bit but when you told him to get back up he did.

Pat: He actually addresses authority very well. He addresses the fact that if it's the case that you know, he was told it was dangerous, he was told he needed to do as he was told, he was told in no uncertain terms you know that there was a hierarchy of structure in relation to his instructions. And he took them. And he took them very seriously. You know when he was told get up he got up, when he was told to rest he rested. When I met him first my concern

was that he wouldn't respond to structure but he is absolutely amazing for responding to structure.

He did try to get away with things, you know "I'm tired, I want to sit down", and you know some part of that in him, and I don't know was it a seek of attention, but the minute he knew he wouldn't get away with it he actually clocked back in so today I think I've learned a huge amount about autism. So for me it was an honour being out with Sean, you know it's so important that we give back, you know we're so lucky that we have our full faculties and everything, and I must say you know to the parents and to the brothers, sisters and things like that, cause you know when you're talking about doing something like that it's a team, and the team not alone goes to us here on the ground today, but you know to me you know Sean is gone this evening. Like it's the people who put in with it day in day out, who actually love Sean to the degree you know where they're fighting for him all the time, what we've done today is small.

Steve: Well what I would say about is that today we celebrated Sean as a person. Yourself and Joe took a chance on him because ye thought outside the box. Ye saw him as a person and not just simply as a person with a disability.

Pat: And it is a person and to me, you know from dealing with Special Olympics and things like that. Like one of the best stories I have is about the Special Olympics. Eight special needs kids stood on the line and the gun went off and they were all going for silver, gold and bronze. The last little girl fell, tripped over and started crying. The second last little girl stopped, then the next girl, then the remaining five. They all walked across the winning line together holding hands.


You could see that passion in Sean and that humanity. That's what it's all about in relation to a person who is very, very special. So we're just glad that we can do anything that we can. We deal with kids all the time in our educational programme. This is to mentor projects that are going on and to help others to achieve their dreams, their goals, their Everests. And no matter who we are we all have them. Whether it's a special needs child, or whether it's you or whether it's me. All our dreams and aspirations, just like that of Sean's are their Everests and if we can help in any way as mentors- and we're all mentors, every single person out there is a mentor, the mother, the father, the brothers, the sisters, you know, the people at school. So if we can help in any way as mentors then we should be doing that, and to keep everything positively focused.


Steve: Just to finish up by saying thank you for the gift that you gave to him today.

Pat: Well, I think more importantly is what we have got out of today has been amazing as well. You know, I hope Sean has got something out of today and that he'll hold it. The thing with it is today was Sean's day and I think for everybody who was on that mountain, including the people that we met, it was an amazing experience to see him, you know, push his way to what was his Everest.

Steve: Pat, thanks very much.

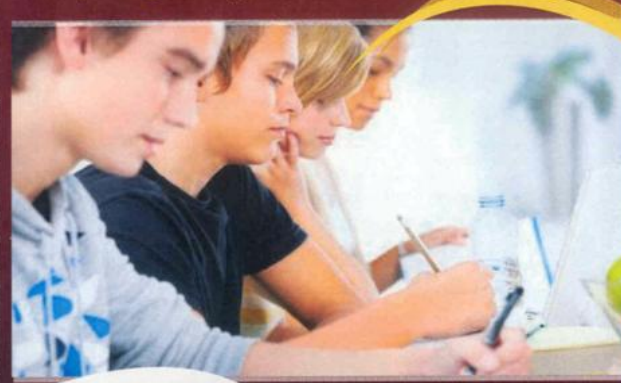
APPENDIX N- Prospectus for 'Facing the Challenge' Seminar (16/03/2011)



The City of Cork VEC 


FACING THE CHALLENGE

- Exploring the Opportunities



INTRODUCING AN INTEGRATED PROVISION FOR STUDENTS WITH AUTISM

A WORKSHOP FOR SECOND LEVEL SCHOOLS
NAGLE COMMUNITY COLLEGE , MARCH 16TH 2011

The City of Cork VEC 

INTRODUCTION

This workshop has been devised to provide schools with an opportunity to meet and discuss the challenges that they will face as they engage in the process of developing an ASD service for students in their schools. The City of Cork VEC and Nagle Community College have been offering an ASD service since 2007. This workshop focuses on our experiences over the past three years and expertise gained through these. It provides an opportunity for the sharing of these experiences and the development of a network of schools engaged in making similar provision available across Cork City and County.

AGENDA

- 9.30 Registration
- 10.00 Welcome from Mr George Roche Principal Nagle Community College and Mr Ted Owens Chief Executive Officer of City of Cork VEC
- 10.15 Presentations (Session 1)
 - Dr Martin Gleeson, Maria Immaculate College of Education**
Understanding the needs of students with ASD's, their educational and personal development from a parents perspective. Preparing as they move into second level education
 - Dr Patsy Daly, Maria Immaculate College of Education**
Preparing staff for the introduction of an ASD service into a school
 - Mr Gus Byrnes, Nagle Community College**
The experience of teachers faced with the introduction of a service for children with ASD's
 - Mr George Roche, Principal Nagle Community College**
The challenge of introducing an ASD service into a second level mainstream setting. Introducing the concept and building staff acceptance. Integrating the ASD service with the mainstream provision
- 11.15 Tea/Coffee

11.45 Presentations (Session 2)

- Dr Noreen Cronin, a parent of a child in Nagle's ASD programme**
The experiences of a parent whose child is currently enrolled in the Nagle ASD service
- Ms Loretta O'Sullivan, SNA, Nagle Community College**
Working with children with ASD's, their parents and staff in the home room
- Mr Stephen O'Leary, ASD Coordinator Nagle Community College**
Developing an ASD programme, focussing on integration and meeting the needs of the pupil
- The National Council for Special Education**
The role and experiences of the Special Education Needs Organizers in establishing ASD services. Support and advice

1.00 Lunch

2.00 Workshops/Discussion Sessions (Participants select 1)

- A. *Establishing an ASD service/programme in a school – challenges for staff and management in the school.*
- B. *Developing an ASD programme that is inclusive and responsive to student needs.*
- C. *The role of parents supporting an ASD programme.*

3.00 Workshop Feedback

- 3.30 Plenary
- 3.45 Finish

APPENDIX O- Letter to Sean from 'Chernobyl Children's International' (16/12/2010)



**Chernobyl
Children
International**



Stephen O'Leary
C/o Nagle Community College
Mahon
Blackrock
Cork

16 December 2010

Dear Stephen

Thank you so much for your generosity and assistance in helping Sean Cronin achieve his dream of climbing Carrauntoohill, to raise funds for the work of Chernobyl Children International.

Miriam, who represented our charity on your Awards Night, spoke very highly of your great work with autistic children and young people, allowing them to achieve so many previously unthinkable ambitions.

Sean Cronin has made many miracles possible for the young vulnerable children in great need in Vesnova Children's Orphanage in Belarus. He has shown such decency and sense of purpose in choosing these children to be the beneficiaries of his extremely generous donation of €725.

We feel so privileged and honoured that you helped Sean in his quest to reach to the top of Carrauntoohill. In Sean's name, his donation will touch the lives of the children of Vesnova and make many miracles possible for them in 2011.

Next year will mark the 25th Anniversary of the Chernobyl disaster and far from being 'history', the accident continues to affect millions – especially children – in Belarus, Ukraine and Western Russia. We will commemorate these children in our work and in our hearts throughout next year and ensure that they will not be forgotten.

Stephen, you and Sean have inspired us in your great efforts and we are truly humbled. Please accept my deepest and heart-felt thanks to you and the staff of Nagle Community College for helping us to continue to serve some of the world's most fragile and disadvantaged children in the affected regions of Chernobyl.

In Deepest Gratitude

Adi Roche
CEO
Chernobyl Children International

Chernobyl Children International is a Charitable Company Limited by Guarantee.
Registered in Dublin, Ireland. No. 211588. Registered Charity No. CHY 11477.
Registered Charity No. in Northern Ireland XR 29624.
Directors: Adi Roche, Mary Ahern, William Keary, Ali Hewson, Michael Roden, Noel Kelly,
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APPENDIX P- Letter to Sean from an Taoiseach Enda Kenny (15/09/2011)



Oifig an Taoisigh
Office of the Taoiseach

15 September 2011

Mr Sean Cronin
Woodhaven
Fortwilliam
Douglas
Cork

Dear Sean

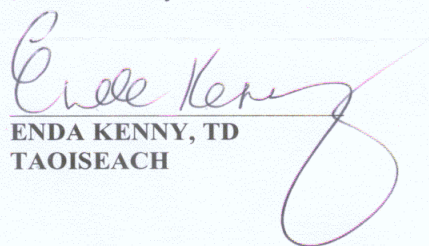
I heard from Stephen O'Leary that you climbed Corran Tuathail in Kerry some time ago in aid of charities dealing with children in Russia. I also know from Stephen that a video was made of your wonderful climb and the purpose of my letter is to congratulate you on this magnificent achievement.

I had the opportunity to walk up Corrain Tuathail with Pat Falvey and Joe O'Leary, Stephen's Dad, and Joe was telling me about your wonderful adventure.

You should be very proud of your achievement and I hope that it inspires many of your classmates to do something equally challenging whenever they feel up to it.

Once again, very best wishes on an outstanding achievement and keep up the good work.

Yours sincerely



ENDA KENNY, TD
TAOISEACH

Oifig an Taoisigh, Tithe an Rialtais, Baile Átha Cliath 2.
Office of the Taoiseach, Government Buildings, Dublin 2.



