

FINDING THE POSITIVE

(exploring the positive value of living with ASD and the challenges blocking its
expression)

by

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ABSTRACT

The language used to define and diagnose Autistic Spectrum disorders (ASD) is overwhelmingly a model of disability and deficit. Without this negative emphasis support services are virtually impossible to reach. Few reports even mention how young people with ASD would wish to be described, or how their attributes, strengths and passions might provide powerful tools to overcome low self esteem, alienation and potential mental health problems. This project worked to uncover and release the strong positive voice of teenagers and their parents by listening deeply to their experience and enabling them to describe and recognize the value they bring to the neuro-typical world. It expresses their struggle to engage with the positive, offers glimpses of hope and laughter, and reflections on that unique experience.

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INTRODUCTION

Rationale

At the start of a diagnostic interview, Attwood's 'Congratulations! You have Asperger Syndrome' is sincerely offered to explain the young person is neither 'mad, bad nor defective.' He went on to describe the talents and abilities which emphasise the benefits of the condition (Appendix 1) (Attwood, 2007 p332).

Luke Jackson's teenage autobiographical 'Freaks, Geeks and Asperger Syndrome' also stands out for its positive and pragmatic account. He insisted that he has a gift, not a disability (Jackson 2002).

However, the vast majority of literature focuses on disability, deficit and difference, with support systems and interventions largely problem focussed. Meanwhile, increasing numbers of young people whose needs are not heard, develop mental health problems and lose hope of integrating into society (NAS 2010). More personal accounts and biographies associating great historical figures with ASD now offer glimpses of the gifted and exceptional, but there is little of the ordinary, normal goodness and value that young people with an ASD bring to the world. That voice is rarely heard. My work supporting families with ASD, and my personal experience as a mother, reveals long battles for services and support, and for understanding of ASD as it is uniquely expressed by each young person. Rarely is any reference made to strengths, abilities or passions.

This study hopes to begin to redress that balance.

Aims of Research

The main aim of this research study is to release the positive voice of 5 teenagers with ASD and their parents, that they might recognize the positive in themselves, and draw away from the overwhelming sense of deficit and disability. A further aim is to enable a developing positive dialogue between child and parent as they share experience and shift focus toward the positive.

Hopefully then, the glimpses of strengths and joys will influence teachers and support professionals to refocus attention to what young people with ASD can offer.

Research Question

The project explores the positive value of living with ASD and the challenges blocking its expression.

LITERATURE REVIEW

Autism Origins.

Kanner (1943) and Asperger (1944), each independently selected 'autistic' as the key descriptor for the group of children they encountered in their professional practice. Autism means 'self'. Each believed the root of the disability was an instinctive or inbuilt issue of 'affective contact' and focussed on the issues of social and communication difficulties, unusual movement habits and the 'puzzling, patchy, pattern of intellectual achievements.' They were also both 'impressed by the occasional feats of intellectual prowess in narrow areas' (Frith, 2003, p8). Wing and Gould coined the phrase 'triad of impairments' defining the social, communication, and imagination impairment which varied in expression depending on age and level of intelligence and with consequent rigid repetitive behaviour (Cumine et al, 1998, p10). They made the important distinction that 'learning disabilities could however occur without associated autistic disorder, though they often occurred together' (Wing, 1996, p21). Wing (1996) concluded that Autism and Asperger syndrome are each subgroups on a spectrum ranging from the most physically and mentally disabled person with social impairments, to the most able, highly intelligent person with subtle social impairment the only disability.

Diagnostic criteria

Various Aspergers criteria exist but Attwood (2007) and Lyons and Fitzgerald (2005) preferred Gillberg and Gillbergs' criteria (Appendix 2) as most closely resembling Asperger's original descriptions (Attwood, 2007, p36). Social impairment plus 4 of the following 5 criteria led to positive diagnosis –

- Narrow interest
- Compulsive need for introducing routines and interests.
- Speech and Language peculiarities
- Non verbal communication problems.
- Motor clumsiness.

(Gillberg 1991)

In 2010 the Diagnostic and Statistical Manual, DSM-IV, 2004) (Appendix 3). would subsume Asperger Syndrome (AS) within the category of Autism Spectrum Disorders (ASD) (American Psychiatric Association, 2010). Clinicians tended to agree that DSM criteria for AS are unworkable in practise (Attwood, 2007, p8). Wing was concerned with the common lack of awareness of the range of severity and individual presentation of the triad. Families whose children might have presented with more interactive, talkative, clumsy, naïve and 'gauche' behaviours along with intense limited interests could easily overlook autism as a possible explanation for their child's behaviour and so not seek help. Secondly, professionals held a narrow view of ASD as a childhood condition, and would therefore not consider it the key to adults who came to their attention (Wing, 2002, p117).

A Fixed State?

Children with Autism often show 'increased adaptation and compensation' and the child who first presented with Kanner's Autism, could more closely fit Asperger Syndrome. (Frith, 2003 p16). Wing also observed the great potential

for 'remarkable progress and movement along the continuum' in children who received early diagnosis and intensive and effective early intervention programmes (Attwood, 2007, p14). She described the socially aloof and silent child who develops a desire to play with other children and who can communicate in complex sentences. Earlier speech and language needs focussed on basic communication ability but interventions were now about teaching social awareness coupled with talking less and listening to others more. Where preoccupation with parts of objects, like repetitive spinning of a car wheel dominated, now there was extreme interest in a specific topic, such as Thomas the Tank. Where early observation of behaviour and play would have suggested significant intellectual impairment, the child would now be confirmed as having a normal IQ level (Attwood, 2007, p14). Szatmari (2000) also identified those who developed 'functional language in early childhood eventually joined the development trajectory of children with Asperger's.'

Challenges of Diagnosis

There is as yet no medical test to identify the presence of Autistic Spectrum Disorder (ASD), or AS in particular. Diagnosis is based on observation of the child's behaviour, and subjective interpretation of behaviour and severity. This is difficult. Non-verbal behaviour including eye to eye gaze is extremely difficult to objectively measure and the boundary between 'normal' and abnormal blurs when we try to measure just how much eye to eye contact fits where on the scale (Molloy and Vassil, 2004, p18).

Frith challenged the 'fuzziness' of diagnostic criteria based on deficits and exclusive diagnostic categories, when a scale of normal and abnormal behaviour which shade into one another, might allow AS as a normal personality variant (Frith, 1991, p23). Baron-Cohen more firmly believed in a full diagnostic assessment of ASD only if suffering a 'clinical level of distress' regardless of demonstrated autistic traits (Baron-Cohen, 2001, p15).

Molloy and Vassil (2004, p18) challenged the 'personal pathology' of the medical model of diagnosis and labelling which then becomes 'infallible truth'

and causes the world to view the difference as illness, needing a medical solution.

This is a double-edged sword. Without diagnosis the potential help that comes with it could be delayed until much later when distress is expressed as challenging behaviour, for example at school transition time aged 11. The Department of Education in Northern Ireland (DENI) stressed the increased organizational, behavioural, social and emotional difficulties created by the double challenges of adolescence and ASD, as they entered secondary school (DENI, 2001). Aged 13, Jackson spoke from personal experience and firmly believed early diagnosis was key to getting both therapy and support at school (Jackson, 2002, p26). DENI deemed diagnosis crucial to educational planning, and urged diagnosis to focus on 'levels of ability rather than theoretical diagnostic subgroups' (DENI 2001, p17).

Jackson rejected neat checklist of criteria, which can cause non diagnosis and 'muddles them and all around them think that they are even more 'freakish' (Jackson, 2002, p30). Gillberg referred to the 'gestalt acumen' of experienced clinicians which enables them to recognize the disorder despite widely varying individual presentation' (Cumine et al, 1998). Put more succinctly 'diagnosing children and adults with AS remains a high art, not a science' (Meyer 2001 p30).

Living With Aspergers:

'With collected energy and obvious confidence and yes, with a blinkered attitude towards life's rich rewards, they go their own way, the way to which their talents have directed them since childhood.' (Asperger, 1944, p89).

How does the parent begin to live with their child's diagnosis, to translate the definitions, the jargon into ordinary life? How does that young person begin to absorb its meaning while getting on with the everyday business of living in this social world of home and school? The challenges may never be greater than when the young person is in adolescence.

Individuals with AS have difficulty with self-reflection, a specific element of 'Theory of Mind' deficit, given this grows out of an awareness of self and of others' (Attwood, 2007 p342). How then do they begin to make sense or translate the label, the theory to their own experience? (Lyons and Fitzgerald, 2005, p41; Jordan and Powell 1996).

One teenage boy may be annoyed to discover his parents had known for some time before they told him he had AS. For him the diagnosis would have allowed him to rebalance the negative self-image he had been holding inside. Another may have found it helped him understand and accept how he found it so difficult to make friends. Yet another finally may have had an explanation as to why he could not get organized for school each day. Having a definition of their condition seems to enable each child or young person to reflect differently on their sense of self, and even somehow legitimized their clumsiness or their tendency to get stuck during some tasks, and their sensory issues too (Molloy and Vassil, 2004, p115). By comparison those with a great need for certainty and rules may find it very difficult to accept and cope with the individual and shifting nature of their diagnosis. The tendency to 'black and white' thinking may confuse if the diagnostic criteria do not seem to directly fit them (Murray 2006, p127). Murray stressed the need for an unfolding process of understanding where information on the individual AS personality and behaviour can be conveyed over time and based on where the person is at the time.

Young people with AS in mainstream school start to become aware of their difficulties, their difference in primary school years (Murray, 2006 p128). Often

in transition to secondary school they begin to experience many failures and frustrations as they witness peers seeming to cope with the extra demands with ease. In adolescence, social and academic worlds become more complex with an expectation of more independence and self-reliance. Secondary school includes the inherent challenges of planning and organization. Subjects require an ability to 'read between the lines' and friendships take on a whole new meaning (Attwood, 2007 p18). All this on top of the normal changes from childhood to adolescence becomes increasingly difficult for the young person with AS.

Parents of children with ASD were found to be 3 times more vulnerable to psychological ill health (Dillenburger et al 2004). Emotional turmoil arose when faced with finding a way to accepting their child's diagnosis and difference (Moyes, 2003; Attwood, 2007; Lasser and Corley, 2008; Willey, 2003). It was a challenge that even the mother of Luke Jackson (2002), that accomplished young AS author, described as painful (Jackson 2003). Alongside her acceptance and even great delight in her family of numerous children with AS, she admitted the immense sadness, tears, envy and then guilt she feels when she notices and then compares her children with 'normal' families. She was quick to admit these feelings were about her own aspirations and expectations for her children; they do not belong to the child. Watching her sons being bullied or rejected, was swiftly followed by swallowing of pity and 'self pity, and a call to action on their behalf' (Jackson, 2003 p223). Willey described the sadness and the worry for other teenagers who might experience the same kind of 'cruelty specially reserved for those with AS' (Willey, 2003 p179).

Appearing Normal

Individuals with AS often present as ordinary to the untrained eye, and so people in general will expect 'normal' behaviour. Significantly higher stress levels among parents of young people with AS may be due to the great efforts to manage situations where they feel it necessary to explain their child's behaviour when it fails to live up to the expectations of others. Where the child in school may achieve outstanding results, or perform with exceptional ability, expectations are raised, yet invariably these are dashed when the child fails to

live up to the achievement or behaves inappropriately. Parents described their own embarrassment and later, guilt, as they witnessed the public display of the child's 'bizarre' behaviour and felt a need to explain it away. They described the increased tension in advance of any situation where public display of the disability is possible. Significantly, these parents believed that the normal appearance of their child was the toughest part of the disability precisely because of the expectations created, followed by the inevitable failure (Lasser and Corley, 2008, p344).

Parents have a life-long dilemma. How much should they accept their young person's 'anti-social' behaviours and let them be or intervene to make sure their behaviour fits in with what we call normal. Just where do they draw the line in seeking conformity from the child around the myriad everyday challenges? Moyes warned of the dangers of attempting to 'fix' or fundamentally change the individual child rather than accept their AS as another facet of their personal qualities, allowing them their 'typical' adolescent rages and mood swings and belligerence. She stressed the dangers of self loathing and depression as a consequence of the pressure to meet expectations of parents on top of those placed by peers and the world at large. Further, she suggested that those adults with AS who consider themselves happy and well adjusted have emerged from homes where 'their individuality was applauded and abilities were supported' (Moyes, 2003, p205). In contrast Williams described the girl who like her parents, was determined to deny the diagnosis of Autism, because this implied 'not being able, being retarded and worst of all being denied a chance of a fulfilled future like non-autistic people' (Williams, 1996, p272).

Williams seemed to scorn the many 'treatments' devised for 'ASD' people as 'seeking to cure epilepsy by teaching people how to 'act normal' during an attack' (Williams, 1996, p19). She described herself being 'buried alive' under the forced façade of appearing normal in order to be accepted, when her true self was not (Williams, 1996, p242).

Young people do what they can to fit in. Willey devised a formula for appearing 'normal', which meant she would simply copy the few peers she thought she could trust. When they laughed she would laugh when they were angry she

expressed anger. She acknowledged that this often worked, though at times it obviously failed too. (Willey 2003).

Those who have internalized their difficulty with self-blame will likely show signs of depression and anxiety (Paxton and Estay, 2007, p180). Attwood (2006 p 33) went further, identifying four types of response paths which young people with AS commonly use to compensate for their sense of difference based on an internalizing or externalizing preference (Attwood, 2007, pp27-28).

Internalizing

Private feelings of Self blame and Depression

<p>Reactive Depression</p> <ul style="list-style-type: none"> • Over apologetic, self critical and withdrawn. • Recognize own isolation but lack skills to fix it • Further ridicule and rejection • Possible suicidal thoughts 	<p>Retreat into Imagination</p> <ul style="list-style-type: none"> • Imaginary Friends or • Seek Alternative worlds leading to intense special interests • Gains social recognition value OR risks withdrawal into fantasy world. • Possible schizophrenia referral
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Externalizing

Arrogance and Denial Blaming Others

<p>Others are the Problem</p> <p>Presents as -</p> <ul style="list-style-type: none"> • Never make mistakes and above the rules and must stay in control <p>But Inside –</p> <ul style="list-style-type: none"> • Aware of social failure • Desperate to hide shortcomings • Get it wrong and misinterpret others motivation as malicious • Cannot admit wrong <p>Endless arguing and more hurt.</p>	<p>Others are the Solution</p> <ul style="list-style-type: none"> • Imitate • Observe from the sidelines to learn • Can be great mimics • Copying at first useful • Begins to look artificial and contrived <p>Can lead to social failure</p>
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Sadly all four coping strategies risk failure because the compensatory behaviour will in turn appear not normal and socially ill-fitting, and may increase the sense of thwartedness and difference experienced by the child. (Attwood, 2006 p32).

Others' Judgements and Expectations

Asperger originally defined 'autistic psychopathy', as an 'inherited personality disorder which overlapped the 'normal continuum'.' It was in the translation to English that we gave that description a further pejorative, negative meaning, often linked with criminality. Asperger himself referred to it as personality characteristics or variants and Fitzgerald argued that the label of 'autistic personality' might have provided a truer reflection of children with Asperger Syndrome. (Lyons and Fitzgerald, 2005 p40).

Asperger syndrome is often viewed as a much milder form of Autism, with fewer obvious language difficulties and higher IQ, coupled with a greater motivation for social contact and relating. However, with this apparent greater ability come higher expectations and the greater chance of failure and rejection (Chape, 2009 p5). Teenagers with AS felt scrutinised unfairly for everything, far beyond what 'normal' children tolerate, and felt the DSM criteria blinded people to their individuality. 'You have to have difficulties making friends, look down at the floor all the time, wave your hands in the air and so on' (Molloy and Vassil, 2004 p92). Jackson rejected the mild differentiation' (Jackson, 2002). Williams (1996) raised awareness of stereotyped responses to difference and reflected 'Having sat around with 'autistic' people who have more empathy, curiosity, imagination or ingenuity than so called 'normal' people, I think its time the mythswere unravelled' (Williams, 1996 p7). Jackson and others, felt the 'double-edged sword' of a diagnosis that creates understanding, but equally turns the person diagnosed 'into a patient or 'case' which requires treatment, therapy or rehabilitation' (Molloy and Vassil, 2004, p9). They suggested no one actually

knows how involuntary labelling of the child will affect these children as they grow.

Lawson wrote of negotiating her way through a world which 'wanted to frog march her into the Neuro-Typical (NT) world, because of the fundamental belief that with ASD she is in some way 'damaged'. The consequent negative and critical messages she received 'may be so humiliating that I cannot bear what I do perceive of myself' (Caldwell, 2006 p141). She stressed the great need for positive input about themselves in order to boost the floundering self-esteem from criticism and failure (Lawson, 2003 p40). This fits with William's experience of parents who 'build their pride on the person's ability to appear 'normal' and intentionally or unintentionally, display disappointment or pity if they falter' (Williams, 1996 p299). Young teenagers with AS struggle to cope with the many demands of secondary school and adolescence in general, and may be driven to try harder and harder, while others simply decide that they are just stupid, or crazy. This faulty sense making could be blamed on those teachers and adults who do indeed demand more effort – to concentrate, to listen more carefully, to make more effort at homework. (Murray, 2006, p128) Indeed Asperger himself warned 'The teachers underlying emotional attitude influences, involuntarily and unconsciously, the mood and behaviour of the child' (Asperger, 1944 p 48). Attwood explained the peaky profile of the typical student with AS who despite a high IQ will have an uneven profile of cognitive and intellectual skills, as well as a different thinking and learning style. (Attwood, 2007 p244). These young people may be doubly disadvantaged. Not only will diagnosis be delayed due to a failure to see through the 'invisibility' of the condition but their behaviour may be misinterpreted and judged by parents and teachers (Connor, 2000 p286).

Further research into pupils with ASD in mainstream secondary schools revealed a great gap between the best and the worst when it came to inclusion and revealed some 'very deep seated values and beliefs' around responsibility for ensuring inclusion and participation. One SENCO said

If you have a head of year who just doesn't take on board that these children are not just being naughty, or whatever reasons they give, and do something about it and lead from the front, then the troops aren't going to (Humphrey and Lewis, 2008 p132).

So, misunderstood and unable to make sense of themselves and their difficulty, the young AS student may well decide the adults are right, that it is their fault they cannot do it, and judge themselves harshly. When Claire Sainsbury's attempts to try harder failed, she concluded that she must in fact have schizophrenia such was the degree of difference and desperation she felt from her peers (Whittaker in Murray, 2006, p128).

Equally disturbing, on the flip side of others judgments of how people with AS should behave, Williams reported how others with an Autism diagnosis have confided in her their reluctance to admit having 'imagination' or creative or fantastic thoughts or mental images, lest they might not be judged as 'truly autistic' (Williams, 1996, p13).

Perhaps then, as proposed by Moyes, since home may be the only place where AS children feel accepted, it is of fundamental importance that we learn to

...acknowledge our children for the unique individuals that they are', treasure the individual for the gift that they are and above all ensure we reassure the child in that belief! (Moyes, 2003 p205).

On the other hand many families treat AS as something to be ignored and a subject to be avoided, or the condition made little of by possibly well meaning relatives. 'He looks fine to me' or 'that's just boys' (Jackson, 2003, p211).

Jackson made no apology for keeping up the persistent fight for accurate diagnosis, for the right help, and for the ongoing effort involved in educating family members and professionals who just do not understand.

Bullying

Difficulties with social communication and interaction, particularly at secondary school, leave pupils wide open to bullying, teasing and consequent social isolation ((NAS, 2006; Whitney, Smith and Thompson, 1994; Humphrey and Lewis, 2008). The typical chaotic environment of secondary schools heightens the social challenges for the student with AS who typically needs routine, predictability and low sensory stimulation. Many secondary schools often do not have the knowledge or ability to cater for those students needs, and so there is increased risk of mental health problems. (Humphrey and Lewis, 2008). This environment describes the perfect ground for the bullying which is so much a

feature for teenagers with AS. In a major report sponsored by the Northern Ireland Children and Young persons Commission (NICCY 2007) teenagers with AS in Northern Ireland raised bullying as the single most important issue in school and spoke starkly of an obvious culture of put downs and bullying modelled by teachers who 'single me out and put me down' or 'started on me for not understanding my work'. Asked to describe their worst experience at school they said 'there is not enough space to describe every minute I spend there' and 'I have been humiliated too many times to pick out just one experience'. Best experiences include 'when I missed the school trip.'; 'changing schools; and 'never had one – barring leaving.' More worryingly the NICCY report also highlighted the perceptual gap between pupils with AS and schools, where schools made no mention of bullying as an issue. NICCY strongly recommended proper training and awareness raising to address the very real problem experienced by so many young people with AS (NICCY 2007).

Self-Esteem

A majority of young people with AS will have experienced many social failures in their young lives and have been open to scorn and ridicule by age peers. Many, despite high ability, become very sensitive, paranoid even, and live with very low self-esteem (Wing, 1996). Bullying creates increased anxiety, depression and lower academic achievement (Attwood 2007). Increased isolation is also confirmed (Hodges, Malone and Perry, 1997). Attwood confirmed that children with AS are more at risk, suffering as they do from low self esteem, and a predisposition to anxiety (Attwood, 2007, p101).

Murray described how everything became focussed on her failure, due to events which damaged self confidence, and no attention remained for anything else This made reaching out more difficult. Hope is lost - 'being unable to proceed with confidence shrinks ones horizons of possibility' (Murray, 2006, p55). This is all the more striking given that children with AS were found to experience emotional loneliness in greater intensity (Bauminger et al 2003).

Anxiety

While numerous clinicians reported observing high levels of anxiety within the adolescent AS population (Farrugia and Hudson, 2006), specific research on the subject is limited.

Autobiographical accounts of adults with AS revealed common references to anxiety due to the 'unpredictable world' (Connor, 2000). Baron-Cohen hypothesizes the anxious or disinterested reaction of people with AS when faced with situations that are unpredictable or uncontrollable. He appreciated how the young person with AS will struggle to work out all the social rules required for survival in the playground, friendship, classroom etc., trying essentially to systemize that which is, naturally, an empathising task (Baron-Cohen et al, 2001). Asperger himself suggested that the absence of a sense of humour, especially when the butt of teasing, may block the defence that would most likely protect, but he stressed how they are invariably never relaxed and carefree (Asperger 1944). Research has confirmed that adolescents with AS have high levels of anxiety on a par with those diagnosed Anxiety Disorder. They also found behavioural problems correlating with the degree of anxiety reported both by parents and the individual. While self-reports showed no reduction in anxiety following treatment, parents reported an improvement in behaviour. All-in-all the researchers recommended better diagnosis and treatment of co-morbid conditions (Farrugia and Hudson, 2006).

The National Autistic Society (NAS 2010) revealed a serious lack of Autism specialist provision amongst Community Mental Health Services (CAMHS) which they claim is responsible for as many as 71% of people with AS being referred with mental health problems. 32% of parents believed CAMHS helped their child's mental health, while less than half believed CAMHS are skilled in communicating with their child. Those that were satisfied believe it was because an Autism specialist was involved. The evidence directs towards effective assessment, diagnosis and intervention which is AS specific (NAS 2010).

Positive or Negative: Disability or gift

Socially inept, but often socially interested ... articulate yet strangely ineloquent,gauche and impractical, ...specialists in unusual fields(Frith, 1991, p12).

Those individuals with AS having an IQ over 130 are sometimes described as gifted and talented (Attwood, 2007 p253.) However, while a high IQ may predict good grades in schoolwork, some children with AS in fact achieve lower than expected grade levels. While teachers and parents agreed that the child is clever, school results often disappoint.

Attwood pointed out the double-edged sword of such cognitive abilities where the emotional and social development of the young person may not keep up. The young person who is extraordinarily able to find a solution or equation for some or other task, may experience the immense frustration of being unable to organize the practical aspects of the idea or communicate his brilliant thinking. Ill-matched to the abilities and greater social functioning of his peers the young person is likely to be further isolated and ridiculed. They in effect can become doubly *disabled* – both socially and intellectually alone (Attwood, 2007, p254).

Regardless, some young people with AS clearly do value their condition as a gift. Hall was clearly appreciative of his gift for reading and Maths, and the fact that he is a MENSA member (Hall, 2001 p57)

Literature which does focus on the positive characteristics of AS tends to point to the exceptional, the gifted, the Savant. Savant Syndrome is thought to be present in around 10% of people on the Autistic Spectrum. It describes those people who though intellectually impaired, display exceptional talents in a very narrow, specific field such as calendar calculation, maths, memory, music, art, and memory. The most well known savant was characterised in Rain Man played by Dustin Hoffman.

Ortiz's mnemonic for Asperger Syndrome was **A**ffirmation, **S**trengths, **P**ositivity, **E**mpowerment, **R**espect. He studied more than 40 people with AS who each demonstrated remarkable gifts and exceptional abilities in very specific areas.

These ranged from the young person with an exceptional ability to calm animals, to Suelan who detected a faulty gas connection to its precise location behind a wall, to Carson who demonstrated his fluent reading on his 2nd birthday. In many of these case studies Ortiz presented people who were initially grossly misunderstood in their exceptional abilities. Travis was arrested by police having been reported by people when seen looking suspicious,

standing out in the rain on a highway for hours on end. Ortiz discovered that he had in fact been analyzing how rainfall failed to clear the road and he could foresee serious road accidents due to hydroplaning. His analysis and solution later proved correct and Ortiz diagnosed him with AS. He avoided the threat of a police charge against him (Ortiz, 2008, p60). Coincidentally Williams related to another situation of a person standing in the rain and proposed an alternative course of action. She suggested onlookers might go out and join them in the rain and take the time and effort to work out what it is they are doing, and the function of the behaviour, a challenge to most people's perceptions and value judgments (Williams, 1996 p287). Of her own savant skills, she said

People with difficulties like mine are not meant to be capable of being so intentionally self expressive, so insightful, so aware..... Some people call these automatic almost unconscious skills 'savant skills'. I call them useful' (Williams, 1996, p7).

Albert Einstein, Ludwig Wittgenstein, and Charles Darwin are historical figures recognized for their great genius, creativity and intelligence. Analysed against AS criteria it is now believed they had AS (e.g. Lyons and Fitzgerald, 2005; Ledgin, 2002; Ortiz 2008). The conclusions again highlight the double-edged sword referred to so often here, that it is indeed both a gift and curse. The potentially devastating impact of poor social functioning, which can be ameliorated by the presence of special talents and interests have lead many to fulfilling professional lives.

The question arises about the majority of people with AS who do not have those clearly defined talents and interests to see them through. While Asperger was at pains to emphasize the many highly positive traits of his subjects – their creativity, intellect, excellent work performance, single-mindedness in following the special interest, Frith urged caution against allowing any romantic notions about genius and unworldliness to cloud the reality of the problems encountered and the help needed by people with AS (Lyons and Fitzgerald 2005, p 310).

Attributes Associated with AS

Lyons and Fitzgerald (2005) provided a clear and pragmatic list of attributes that apply to living with AS.

Above average or even superior IQ.
Specific cognitive style
More object centred than people centred.
Very accurate at perceiving details, good eye for detail
Strong but narrow interests
Superior in systemizing e.g. Maths, engineering, music, mechanical
understanding, computer science.
Creativity, originality – literature, music, inventions, science, linguistics,
Excellent memory (good rote memory skills).
Savant abilities/giftedness
Strong focus of attention. (Lyons and Fitzgerald, 2005 p47).

Applying these characteristics to the employment situation, Attwood suggested the following attributes should be included in an appraisal of an employee with

AS–
Reliable
Persistent
A Perfectionist
Easily able to identify errors
Technically able
In Possession of a sense of social justice and integrity
Likely to question protocols
Accurate
Attentive to detail
Logical
Conscientious
Knowledgeable
Original in problem solving
Honest
Likely to thrive on routine and clear expectations (Attwood 2007 p295).

In stark contrast, the DENI Task Group report on provision for Autism in Northern Ireland almost exclusively dwelt on the deficit model of AS. No positive behaviour characteristics are listed, and fleeting attention is paid to best practise recommendations where ‘pupils with ASD need programmes which identify their individual needs, learning strengths and difficulties.’ (DENI 2001, p171). In contrast, the Office for Advice Assistance Support and Information on Special needs (OAASIS) made many efforts to emphasise the positive qualities of young people with AS and essentially recommended educators

Focus on the qualities and the strengths that an AS disorder can bring. Find them, Develop, celebrate and reward them. ‘Enhance the best while you support the rest. (Gething 2003 p3).

Reports on adults diagnosed in adulthood found that the individual’s reaction varied greatly based on how they viewed Asperger Syndrome – as disability, difference, or advantage. This in turn was shaped by their previous experiences of services. Many had been misdiagnosed with other mental health problems which led to failed interventions and increased feelings of isolation, of not fitting in, and of being different. Diagnosis generated feelings ranging from elation and relief to loss and anger, and influenced both their perception of AS and their self-perception. Indeed many recalled AS having been mentioned early on but not pursued to diagnosis, probably due to the social stigma attached (Punshon et al., 2009, p265.)

In contrast, only one of a group of young adult teenagers had a wholly negative or deficit perspective, while the rest generally felt the positive qualities of the condition outweighed the bad. This boy desperately wanted to rid himself of his AS, seeing it as a ‘lifelong disability with zero benefits’, experienced very low self-esteem, and blamed the AS for all his very real social difficulties. For him AS explained his intense frustration around friends, shyness and his difficulty in judging social situations, in particular dating (Molloy and Vassil, 2004 p20).

Special Interests/Obsessions

One boy who appreciated his AS diagnosis, experienced what he called 'intellectual joy' from his ability to concentrate and become completely absorbed in a given subject (Molloy and Vassil, 2004 p 20). Luke Jackson also came close to describing that joy as he described the difference between compulsions and fascinations or fixations. He stressed that the fascinations were great for providing a sense of control and a key way of relieving stress and that 'we actually do dearly love the things we talk about – It is not just a weird quirk of AS.' (Jackson, 2002, p56).

Jackson advised concerned parents and teachers to leave well alone unless the child was demonstrating a compulsion which could be dangerous or have a very negative effect on the young person (Jackson, 2002, p56).

Families who initially struggled with a wholly negative focus after diagnosis can soon shift to seeking out those behaviours that would allow new skills to develop. Since special interests will likely provide the platform for expressing the child's strengths, this coping strategy can serve the family well, increasing the self esteem of the child and giving focus to their 'unique gifts and thought processes' (Lasser and Corley, 2010, p338).

Outcomes

Asperger predicted a positive outcome for his subjects believing their special interests would enable social integration, and that integration would be more likely for those with AS than Kanner's Autism (Frith, 1991, p87). Kanner supported this notion and revealed how the majority of the 96 children he had seen remained highly dependant, many in care. Numerous outcome studies strongly predicted that higher IQ is associated with better outcome, and that those with AS have the better outcome in measures of academic progress, self-help skills and social interaction than children diagnosed with Kanner's 'childhood autism' (Lyons and Fitzgerald, 2005, p10). Asperger himself remained buoyant hopeful and valuing of young people with AS.

Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements. (Asperger, 1944 cited in Frith 1991, p88).

He largely put this down to their 'narrowness and single-mindedness, as manifested in their special interests' (Asperger, 1944, in Frith 1991, p88) and this fitted with Kanner's diagnostic criteria of 'persistent preoccupation with parts of objects' which still holds in DSM-IV_R (Appendix 3). Their original work gave rise to Frith's 'weak central coherence' theory (Happé and Booth 2008 p52). Happé and Frith shifted emphasis from a deficit model to a preference model, or 'processing bias' that can be overcome. Instead of emphasising the inability to form a coherent whole from a range of stimuli, individuals with ASD were described as preferring to focus on small key details that others tend to miss. Baron-Cohen's 'hypersystemizing' ability theory, suggested that the frequent ability of people with ASD to function very skilfully in fields like maths, physics, and IT was directly related to the innate coherence of such systems. His Autism-Spectrum Quotient (AQ) self assessment outcomes revealed how they scored higher than individuals trained in more human or life-centred sciences of medicine and biology. Mastering these fields of work depends on a keen ability to stay focussed on fine details which collectively form a logical system of meaning. (Baron-Cohen et al. 2001, p14). Happé and Booth (2008, p152) contended that the inability to globally process is in fact an outcome, a 'secondary effect' of superior local processing'. Consequently, Baron-Cohen argued for a 'difference' vs. a 'deficit' model evidenced by the strong desire for children with AS for collecting categories of objects and information, their deep interest in how systems work, their fascination with patterns, numbers, lists; their abilities to take note and remember things that others may not and their excellent eye for details' (Baron-Cohen, 2000, p491). This emphasis on positive skill rather than deficit aimed to shift perceptions to a valuing of the person with AS, and a return to Hans Asperger's positive approach to the subject.

When Lianne Holliday Willey received her adult diagnosis she was 'exuberant' saying 'That's why I'm different, I'm not a freak, or mad.' (Attwood, 2007, p31).

Her self-affirmation pledge could support many through diagnosis :

I am not defective. I am different.

I will not sacrifice my self-worth for peer acceptance.

I am a good and interesting person.

I will take pride in myself.

I am capable of getting along with society.

I will ask for help when I need it.

I am a person who is worthy of other's respect and Acceptance.

I will find a career interest that is well suited to my abilities and interests.

I will be patient with those who need time to understand me.

I am never going to give up on myself.

I will accept myself for who I am. (Willey 2001, p164).

DESIGN AND METHODOLOGY

Not everything that steps out of line, and thus 'abnormal', must necessarily be 'inferior'. (Asperger, 1938).

Introduction

Autistic Spectrum disorders are largely expressed in a framework of impairment and disability, which is likely to influence how both the young person diagnosed, and their family, judge and value their own experience.

The aim of this research study was to begin to reveal the positive voices of young persons with ASD and their parents, through enabling them to recognize and describe the value they bring to living in a neuro-typical world. A further aim embedded in the research process was to enable a positive developing dialogue between them as they shared their experience of living with an Autistic Spectrum Disorder (ASD).

The research methods were based around key themes identified in the literature and built on the following key research questions-

What personal characteristics and attributes do you value most?

Or What do you like about yourself?

What would you like the world to know about you?

What things make it difficult for you to experience yourself in the positive?

What would make it all a bit easier?

Or What support would help?

Further questions from the parents perspective included –

How is the balance between positive and negative or attributes/deficits lived out at home?

What gets in the way of celebrating the positive in your son's life?

How does school work with the positive attributes?

Key Research elements

The research process would include

- unstructured/semi-structured in-depth interviews with 5 young people and their parents.
- examination of documentary evidence including educational statements and assessments.
- completion and analysis of adolescent Autism Quotient (AQ).

Ethical Considerations

Careful consideration was given to research ethics throughout this research process. Young people with ASD are rightly known as a vulnerable group and so procedures ensured full parental consultation and involvement before, during and after the research process.

The social and communication impairments which come with ASD called for plenty of explicit opportunity for checking understanding, expressing any discomfort with the process, and even calling a halt to proceedings, so comfort levels were regularly checked and explicit instructions given. Parents played a key role in communicating understanding.

Diagnosis tends to bring with it a seemingly endless line of professionals probing, investigating and intervening in the lives of young people with ASD. As the family can be hard-pushed to see anything in it for themselves, and experience a 'medical model', this research study has been devised to prevent an experience of 'research-fodder' (Robson 2007 p.101).

Hence the interview process allowed plenty of time for reflection around key questions, and shared exploration between parent, child and researcher to allow voices and stories to emerge around the real life experience of the families.

Numerous opportunities were provided to ensure the data gathered belonged to the participants and not the researcher, with regular reflective listening and

summarising offered to check meaning had been correctly received and empathically understood. Further, based on the researcher's professional client centred therapeutic and learning experience, the core conditions of empathy, congruence and unconditional positive regard underpinned all communication with participants (Rogers 1989) enabling an openness of expression between child and parent and with the researcher.

In order to redress any perceived power imbalance all were offered opportunity to receive copies of transcripts; to view results before and after publication, and to withdraw consent to any or all of the data gathered.

Dual Role

As parent of a teenage boy with Asperger Syndrome, the researcher was keen to offer her own son and husband the opportunity to participate and both volunteered.

Whilst this provided the researcher with added insight into participants' experience, the other parent participated in the interview and reviewed transcripts, to ensure his true data was not contaminated. The other parent also reviewed written results and discussion to ensure true reflection of both parent and child input.

The integrity of participant data would be further assured by presentation of much narrative, as transcribed, to let the data tell its own story as far as possible. (Shelef, L. 1994).

Given the risks of 'going native' (Robson 2007 p.87) due to the researcher living with some of the same practical and emotional challenges, clear boundaries were set on involvement with participants, limiting this to agreed data gathering methods and feedback. As a therapeutic practitioner with the ASD community, the researcher is also used to holding the therapeutic boundary, but as a safeguard sought clinical supervision as a means of managing her own emotional response. (Mearns and Thorne 1988).

A benefit of researcher family participation meant that the son and father would each feel more able to declare boredom, frustration or any other unease with the interview process or lack of clarity in questionnaires, and the insight gleaned enabled greater care and attention to process with other participants.

Procedures

Initially, the research procedure was designed to include a short focus group with young participants. However, numerous face to face invitations, through four separate ASD teenage networks, failed to attract more than 2 interested parties for a focus group, even though great care was taken in clearly spelling out the purpose, design and involvement required by the young people, and allowing plenty of opportunity for questions and clarification. A further offer of such a focus group where young people could further explore ASD was made following interviews, but only one of the five participants was interested in such a gathering. This is perhaps not surprising giving the challenges group work often poses to young people with ASD, and their repeated earlier experiences of interviews, assessments etc.

Consequently, the study involved 5 teenage boys with an ASD diagnosis and their parents to ensure substantial data could be gathered. All boys attended mainstream school and had a diagnosis of ASD.

A brief Introductory letter and consent forms were provided during support group sessions (Appendix 4) and potential interested parties provided contact details. Interested parents were phoned to provide further details and confirm their interest in taking part and clarify the research. Written consent was given by both child and parent. Interview dates were then set up at a choice of location – their home, the researcher home or a neutral meeting place. All chose to be interviewed in their own homes.

Invitation letters included assurances of anonymity and confidentiality and assurance that withdrawal from the research at any stage was perfectly acceptable. Further assurances of anonymity and name changing were given at start of interviews when permission to record interviews was sought.

Semi structured Depth Interviews

Semi structured in-depth interviews allowed maximum opportunity to encourage and reveal both the young person's and parent voice and perhaps as importantly, enabled a dialogue to develop between child and parent around ASD, creating a shared positive experience. Two participants and their parents volunteered after a young persons' support network meeting and another two volunteered after a parents' invitation presented during a parent support group. Whilst some guiding questions (Appendix 5) were drawn up to demonstrate and inform the potential depth and breadth of the data gathering process, both for participants and researcher, the researcher sought to enable depth interviews which would provide a therapeutic quality to the interview, thus enabling richer more meaningful reflection and dialogue. (Robson 2007, p.75).

Parents were asked to consider if separate or joint parent and child interviews best suited their young persons needs and comfort. In two cases parents described their own discomfort in discussing their son in his presence and opted for separate interviews followed by a joint sharing interview, where child and parent were invited to share anything important or relevant that had come up separately, including how they had described their valuing of their son. In one case, the boy though interviewed separately, wanted some questions to be asked of his mother as he felt unable to answer. Rather than make this a procedure controlled by the researcher, he was invited to ask the question of his mother directly and to hear the response. In this way dialogue could build between them.

Releasing Child and Parent voice was the core focus of this research, so that they might hear themselves, as much as provide data for the research project, and so entirely qualitative data was sought.

Before interviews parents were asked if their son could have sweets and these were provided during interviews. Permission was given to record the interview and in some cases the boys wanted to inspect the equipment used. No notes

were taken so all attention could be given to the participants. Each parent child Interview lasted around 3 hours with short breaks as required.

Documentary Evidence

Parents gave permission to copy some or all of Educational Statements and formal Assessment and diagnostic reports, so analysis of that data could be made later. Parents also referred to these documents in trying to identify any positive supporting behaviour by schools. They were later scrutinised for their focus and the language used, and to determine the emphasis on strengths and attributes vs. deficits and disability. Any specific references to special interest talents and skills were identified and comparisons in classroom assistant provision or other support activity noted. Summaries of the main features of educational statements were created. (Appendix 6).

Questionnaire

The Adolescent Autism Quotient (AQ) (Baron-Cohen et al 2006) requires a parent to complete it and was designed to be short, easy to use and easy to score.

Whilst never intended for use as a diagnostic tool, it was used in this research to provide a present day snapshot assessment by parents of the degree to which their sons displayed autistic traits. It might also have provided comparative data to that given in documentary evidence. Parents posted completed questionnaires in stamped addressed envelopes provided.

Limitations of the Research

It was unfortunate, if not surprising, that the initial intention to include a focus group for young people around finding the positive voice of ASD/Aspergers was not possible, given that only 2 individuals in the social groups approached were interested. As an aim of this research project was to enable a developing positive dialogue between child and parent and to enable young people to hear

the positive value in themselves, focus groups would have created a very worthwhile creative strengthener of their voice. As a parent of a teenage boy with ASD, the researcher had to beware personal biases and experiences which might limit data gathering and interpretation of findings. Every effort was therefore taken to remain objective, maintain an open question approach and have transcripts checked for validity and authenticity. The researcher relied heavily on her significant professional experience as facilitator of personal growth and learning programmes where the learning agenda is clearly rooted in the individual and served by the facilitator as it emerges. (Rogers 1983).

Parents may already be overwhelmed by the experience of ASD and embarrassed to be heard, given the potential 'heartache and feelings of inadequacy and guilt that are totally undeserved' (Wing 1996, p.92). Parents and young people may be unable to locate their positive experience given that depression and damaged self esteem are notably high with ASD (Howlin 2003, p.20). The quality of listening provided by the researcher aimed to redress the balance.

Analysis of Data

Interview tapes were transcribed by the researcher to ensure every nuance, partial sentence, and pause was recorded. Questionnaires were returned complete and documentary evidence analysed for further qualitative data, insight or new information.

Transcripts were analysed for emerging themes and each theme presented with specific quotations from the young people and their parents. A pen picture of each boys experience was provided as told by him and his parent under the most important themes, as judged by the amount of attention paid it by participants. Significant narrative excerpts were presented from each participant's story to allow a thorough picture of each individuals experience to emerge and to highlight similarities and differences in experience. Where numerous quotations are made for any theme these are attributed.

Participant's experience of the research process and its impact on them was presented and analysed as any other results theme, to assess the value of the positive emphasis of the project. Results were examined against literature and questions posed to inform future research potential. All in all results and discussion were presented to allow the reader to

Enter into the context ...not to discuss or analyze, but rather to experience meaning. The data seems to answer questions by itself (Shelef 1994 p.1).

RESULTS

Results focus mostly on significant narrative by children and parents as they attempted to express the positive experience of ASD, and their struggles within that process. This was a unique experience for most. Results are presented through natural themes that emerged. Documentary evidence was also examined.

School

School experience dominated much of the interviews for four families. Those four young people had virtually no social experience outside of the school setting, spending all other time at home. Traumatic experiences had made a significant impact on the lives of at least four of them and their families.

David

David (15) was completing 4th year having spent 2 successful years in his current school. A 'traumatic' first year in Grammar school ended when his parents decided they had to change school as his physical and mental health were both deteriorating. There were numerous incidents of 'bullying', numerous detentions and increasing difficulty communicating with the school about David's AS support needs. David was increasingly anxious disorganized and threatening self harm. Finding any suitable alternative placement proved very difficult without board support. He then spent a year 'recovering' in a small and supportive new integrated school though he needed greater academic challenge. His parents were very aware of his low self esteem and feelings of 'shame' and 'failure' from first year. He finally moved to the parents preferred Grammar school at the end of 2nd year. Asked in the first question about the best things that had ever happened to him, David said:

Moving out of XX school 'cos it just wasn't the right school for me. Like I couldn't really move forward there. I'm pretty happy where I'm at now so it's good.

David's father talked about the school experience a lot. He was at pains to describe the difference between schools in first year and now and how much more positive life now was for David -

I'm not sure what the mechanism is but somehow he's socialised into this school to a remarkable extent. I don't think that's about the academic - its more what goes on between him and the other pupils. It may not be anything to do with actions on part of the staff or somehow they're allowing space for him to be himself and in being himself he's making friendships. Compared to XX.... It was awful he was a kind of whipping boy for the neurotypicals, and the teachers weren't much better if at all. In some ways they were worse, they should have known better.

He went on -

Is it to do with direct coaching cajoling or more to do with providing the environmental conditions in a more subtle way that has enabled him to branch out?

David described the first years' school -

Getting in trouble all the time. Always wrong. They were obsessed with punishment. It was too rigid and strict. No not just my fault. I think I was just not ready to go to Grammar school at that stage.

Researcher: What's different in this school?

David: They don't punish you as much. I've never had detention here.

David's father: I haven't been called to a single emergency meeting to discuss D's behaviour- not one.

David: I've talked them out of it most times. (Both laugh).

Father: It seems there isn't a blame culture there. They are all rooting for the students to do as well as they possibly can. They're there to serve the needs of the students. They're not there for their petty agendas. They (First school) were all competing against each other and against the pupils. It was all about keeping everybody else down.

David reflected on the first year school experience with a sense of responsibility for the outcome –

I think maybe even if I went to this school at the start I might have had to leave it. I think it was partly my attitude at the time. It was partly the school. Other people do alright there don't they. So it must have been me.

He also described himself being bullied in first year, but not physically and now 'not too bad'. School now was mostly boring! David has had a full time classroom assistant since Primary 5. He is not mentioned at any time in the interviews.

Craig

15 years old and just completed 4th year in Grammar School, he was 'excluded from school early in 2nd year after a 'serious mental health breakdown'. This

followed a number of behavioural incidents at school, and 'constant complaints of 'bullying' and name calling when he became increasingly anxious and self harmed. Neither Craig nor his parent gave any detail of this school period and educational psychology and school reports at that time state 'he complained of bullying by peers and older pupils which when investigated appeared to have little foundation.' After a four month inpatient stay in a child and family centre, and an AS diagnosis, he made a phased re-entry to school in the summer term. Full- time classroom assistant support was then provided. Craig reported other pupils as saying how they

hate your wee helper lady. She's always in the way.

His own view was that even when they were just playing she broke it up. He is happy to let her organize his books and files. Craig did not refer to his earlier experiences at school but made a number of references to other school children being stupid –

Stupid questions in Biology by Stupid people.
I'm very good at spelling. I just can't believe people who say I done or I seen.
All the idiots in my school talk with the same sort of voice.

When asked what would make it easier to stay positive he said –

If people were just more naturally kinder. If they could be nice to people they don't know. There are a lot of people who don't know me.
Most of them are jerks. It's like 'My friends laughing at him so I'll just laugh as well.'

Craig's mother, reflecting on her own tendency to focus on the negative contrasted school now with the traumatic 2nd year experiences.-

You are able to ignore now the things that you got angry and upset about.

I think the good does get lost. Not as much now as it did in the past. He's in a bit more settled place now, more mature. Obstacles that would have knocked him back before he takes in his stride more now. So you do start to feel a bit more positive. A few years ago I used to wonder if he would get back into school, whether he would get to 5th form and come out with a single GCSE. Let alone get a degree.
Although it was pretty horrible for all of us he has come out the other side stronger.

Keith

Keith 12, was just finishing first year in a local mainstream secondary school.

The family were 'fighting a tribunal' to have Keith statemented as there was a

dispute over non diagnosis by the Education board and an Aspergers diagnosis by a private Educational Psychologist.

His father reported about 12 detentions in the first few months for 'not having homework done or something', These have now stopped and his father believes this is since he challenged a detention for being late and told the head-teacher 'See you In court' .He believed the school were breaking the SENDO (Special Educational Needs Disability Order) by punishing a child due to their disability.

Keith's father felt the school were now-

being very careful with us now going through a tribunal. Because if they are seen to do anything with K then he must have a need. I can't understand about the statement because it would help them in school. But I know they are cutting back on statements.

When asked what positive things he'd like the world to know about Keith his father clearly spelled out the distress over statementing and the school experience

What we're fighting for as well as the statement at school is for them to show us some respect and understanding as to why we want Keith to get help. The school just aren't listening.

As for the SENCO their 2 hour training ten years ago just doesn't wear off on me. They're not listening to the parents at all.

He visited the school before Keith started to explain his need and the numerous small things that could help him settle in, but believed none of these had been put in place.

Keith also has a diagnosis of ADHD and explained 'It means I can't pay attention and I get hyper.' Though his father thought he 'wasn't too bad with that' Keith retorted 'You should see me in school.'

Peter

Peter, almost 16, had just finished formal classes for 5th year and was entering study leave before GCSE exams. He changed secondary school after 3rd year. He moved school because of 'severe bullying' leading to 'obsessive behaviour at home' and attendance difficulties. Both Peter and his mother made numerous references to his deep unhappiness during these years. During his first term of

4th year the new school sought a full assessment of special needs by the board. Coincidentally that year CAMHS had instigated an assessment for Autism and he was diagnosed with ASD in that year. He had been diagnosed with moderate learning difficulties aged 6. Peter had not had a special educational needs statement since primary school, though he did get some classroom assistant support until this year, when the board withdrew funding. His mother said school was now 'chaotic.' -

He can't organize books or timetables or even homeworks. It's in his IEP they were to do that.

Asked if they did she replied 'Sort of. Not Really.'

His Mother talked about how Peter had always hated secondary school –

Now he's on study leave and his routine has changed. It's like he realises he won't have school anymore. He 'mitched off' school and he came and told me and he told the teacher, and got detention. He said he was never so bored in all his life and wouldn't be doing it again. He said he was fed up with school and had had enough. He has never liked school.

Peter was clear about school -

I put my head down and close my eyes. School doesn't interest me. School bores me. I'm always tired so I am. Thankfully I'm off for study leave now.

He was also clear how he much prefers technical college where he goes from school to do sheet metalwork because he -

Get to meet loads of other people 'cos you are in with other schools. I prefer to chat to people and relax rather than head down and knuckle down the whole time.' We chat a lot and do work at the same time. I'd rather be able to chat to people.

Michael

Michael age 13, had just completed second year at a local secondary school where he receives classroom assistance, partly shared, for 15 hours per week.

He has had diagnoses of ASD, ADHD and 'Developmental Co-Ordination Difficulties' since 2005, aged 8, and has some 'speech and language challenges.'

His mother felt sure it is a good placement for Michael, and reported much less need to be present at school than in first year.

I'm much more stepped back. Because it's a controlled environment and nothing will go too far.

For her the verbal agreements with school obviated the need for more formal agreements through his statement.

Michael was very matter of fact about school life in general and at very outset of the interview was quick to talk about being bullied and being suspended in first

Year-

I like my form teacher. Some people say I have teachers wrapped round my little finger. But if I get into trouble she isn't so nice. I got suspended last year twice which I didn't like much. I haven't been in trouble once this year.'

I didn't like it. First for one day then 2 days. I lost my.....(loses concentration). It's from touching girls behinds. One of the times I didn't even notice and got suspended.

Michael's mother explained -

First time he was upset about a pound coin. He was crying. Someone came near him, crowded his space, he didn't understand. He threw his arms out and caught her skirt. It lifted her skirt. School say this is mainstream and that's not acceptable by anyone and this is how we deal with it.

She was quite accepting about the second time, and how the learning hadn't done him any harm -

Second time was more deliberate. Totally different. He knew exactly what he was doing, that it was totally wrong. That was it. Straight out.

All in all mother accepted the school approach and when considering how they valued Michael said –

They do value him. There are a few teachers who would be brutally honest and say he's hard work. But they don't dislike him it's just 'this is what we are working on.' He's got to learn to conform to social norms. It can't only be him. There's twenty odd of them in class. Other people have got to learn.

Asked what he'd like teachers to say about him, Michael simply answered

I don't know. I don't care.

Bullying

Four of the five young people raised Bullying early in the interviews and without any questioning or prompt in that direction.

Craig

Craig began our meeting showing the cuts on his arm and leg from an assault in the playground that day. His Classroom assistant was not on duty, whereas normally she would be.

Craig: Today my friend saw the incident and he knows who it was.

Mother: I think the war wounds this time are pretty clear, and can't be disputed.'

Craig's mother felt strongly that remaining focussed on the positive at home was most challenged by the regular conflict in school -

When there is conflict at school you always feel you are caught on the back foot. 'What has Craig done if anything to initiate it?' You're on the defensive, and almost apologetic. If there's been a fight or a disagreement, it falls more on Craig because he is the one with the issue.

Falls more on Craig as being responsible. Other kids club together and side if there are witness statements. If they are part of the 'in-crowd' they side together and give one version. They didn't see anything. Craig has one version and so has no-one to back him up.

She generalized to the regular experience of conflict involving Craig -

A lot of time it can be something thrown or a bit of shove, but maybe Craig acting the lig has provoked a reaction and whilst there is maybe no excuse for what happened, it's perceived thatthis is why the Classroom Assistant is there... and there's mitigating circumstances.' Craig has a diagnosis but these can be explained away.

She did not use the word 'bullying'.

Keith

Keith's dad described the same kind of regular conflict in school where 'blame' or fault seemed to end up with Keith:

You'd be the one to get a detention for it. Whatever he tells the truth about it. The others lie and he can't get why they lie about it. He's starting lifting chairs and pulled the glasses off someone's face on two different occasions. He slapped another pupil in the face.

And I get told off for it. In the middle of class. I get annoyed and act back.

Keith had described why he didn't like school -

People in my class. They trip me up, push me into the wall and tackle me
Everybody in my class calls me psycho now.

His father was at pains to explain the frustration Keith feels and how he retaliates.

Someone pushes him in the corridor and Keith pushes them back, that rough horse play, and the teacher would see Keith pushing that person.. Keith gets told off and he says 'He pushed me first.' The other kids don't like him telling, like grassing up. And he gets told-off for answering back. He would say (to the teacher) they pushed me first, what are you going to do about that? Then he gets told-off for being rude to the teacher. Then he starts shouting at them. It's because they don't listen to him.

Keith's father described the incident when Keith had ripped up his French book in class because he was frustrated and didn't understand French. When the teacher told him off in French, Keith asked if she could not speak to him in English and was then accused of being cheeky. For his father, this was a straightforward 'Asperger' request but the teacher had written home complaining about the cheeky behaviour.

Peter

Peter named Bullying as the issue when asked to consider positive things about himself. Quietly and thoughtfully he said -

I went through 3 years of bullying there. It's had a huge impact on my life. It really scarred me. People think it's a small scar like on your arm but it is a scar that goes right across from there to there (gestures over body). It's scarred me a lot more than people think it has.

Stuff that was said to me but I forgot about it but I realised it's had an impact on me. I realise its hard to keep focussed but I try to put that to the back of my mind.

While she did not go into the detail of Peter's bullying experience in his previous secondary school Peter's mum said starkly –

He had an awful time at x school. A lot of bad, bad things happened to him. He's still terrified of them. So much so that he won't go into town in case he might meet some of them. Since moving school things are a bit better.

She added that if he sees teenagers in the street from his window Peter will shy away because he is afraid of them.

Referring to his recent disclosures about being depressed, she said –

All the bullying he had for years. Even when he moved school some of it went on.

Michael

At the very beginning of his interview, unprompted, Michael told me about how at school he gets annoyed with other boys who seemed to tease him. He said they did 'lots of stuff' and was specific about name calling –

They call me a name I m not particularly pleased about. The word is 'skinner', and I don't like that name.

To deal with it he tells the teacher or 'helper person' but said it didn't stop them. The problem mostly occurred in the taxi they share, and that because this is not a school responsibility, there is little that can be done.. She was pragmatic about the bullying –

Well it's life. It happens. Because it's going to happen in real life. This is life. This is out there. He needs to learn how to handle it. It's me trying to help him grow up.

Asked what he would like to change about school he wanted to change the boys bullying him. Another time when asked about how people are nice in school he said

Nice isn't in my vocabulary. Bullying isn't nice.

Valuing the Positive

All the young people had real difficulty talking positively about themselves.

I'm worried others will think I'm bigheaded if I say I'm good.
I can think more of the bad stuff that I can about the good stuff.

Invariably they looked to their school experience to assess themselves and there was considerable overlap in the subjects they thought themselves best at including Sciences; Maths; Art; Computing.

Three of the boys really wanted their peers to know, above all, they were smart-

Craig: I'm ok when people take time to get to know me.

Craig: So many people think I'm some sort of complete idiot and don't even know me.. some complete...can't think of the word.

Keith: Awesome, smart, cheeky/bad, artistic....smarter than them.

David: Clever. Laid Back. Funny. Smart and chilled out.

Creative Writing

Three enjoyed creative writing and parents confirmed their talent. .David writes rap and had just been published in a national young persons poetry book. It might give a sharp insight into his self-image. (Appendix 7)

See since the moment of birth
I've been the most hated on earth
And it's gonna be that way till I'm under the dirt,
'cos there's something about me that you all despise,
something scares you away when you look in these eyes
And I never knew what it was,
Guess I never will,
It's a disease that can't be cured by a pill.

Keith was shocked to discover his parents went into his 'safe' box and read his writing. He said he wrote- 'Facts about people'. Asked 'What facts?' 'Emotions.'

Craig also writes and had an item published in the school magazine.

Art & Making

Four of the boys really enjoyed art and anything construction-based, but felt stifled by having to do set projects.

Learning Memory

At various times boys referred to their ability to learn information without trying, though they were unaware that this was a talent or anything special.

Peter: I just look at the screen once and take it in. A bit like the way some science genius can take stuff in. It relaxes me.

Craig's mother: You've a very good memory which is how you get by with no revision.

Craig: I never revise. I just glance over the pages.

Keith: I got top marks in my history exam. And I got no questions wrong. I didn't revise for any exam I did.

David most appreciated his own growing skills in skateboarding, martial arts and ParKour. He recollected how finding ParKour had been the best breakthrough in his life because it allowed him to develop physical skills of movement and balance which he knew he had been lacking before, and how this had led on to much of his other development.

Parents Perspective

Parents also found it difficult to express what positives they valued about their sons. Sharing their thoughts with the boys later, there were numerous emotional moments. It seemed such conversations had not happened before.

Some common traits included – Funny; Sensitive; Creative; determined and Focused Concentration.

David's father expressed real appreciation of him

He doesn't see the difficulties of doing some things creative or attempting things you wouldn't normally. He just practises and practises until he has mastered it. He has a lot to offer. He's talented at a lot of things and he's quite sociable most of the time. He has lots of good ideas. He's very articulate.

He does a fair bit of fairly deep thinking and off at tangents.
He has a myriad of talents.

Very pragmatically Michael's mother embraced her sons' part in the family-

He's my son. It doesn't matter what he is but he's still my son.

Sensitivity

Three mothers revealed how emotionally sensitive their boys are. Michael and

Peter tended to cry easily if scolded at all.

He's quite gentle and is very easily hurt. If I tell him off, he cries.

Craig's mother said-

He's extremely oversensitive to everything, always emotionally aware. Always emotional extremes. If he was sad it was trauma time. If happy he was manic. With him it wasn't lack of empathy.

Michael was quick to tell me how he did not like his father shouting.

Invited to share how she valued Craig, his mother said -

You are very kind and affectionate. Very smart and you can be very funny sometimes.

There was a long pause and they hugged....

You're a big softie.

Craig: 'Hugs don't show on the recording.'

Three mothers revealed the boys tenderness and how they showed real care and concern for others, do not see the bad in others and are keen to help others in distress.

Peter's mother: He has a good heart. He does my heart good. There's not a bad bone in his body. 'His simplistic view of the world is so refreshing.'

Michaels mother: He's never going to intentionally hurt someone or annoy them.'

Peter's mother: 'I'd need to be careful if he's out there in the world. I want the world to be gentle with him.'

David and Keith seemed to reserve their tenderness or sensitivity for their writing (Appendix 7).

Humour

Three parents clearly valued the laughter and humour their boys brought to the family-

Keith's father: A lot of innocent adlib that makes us laugh. You think you're talking to a 40 year old. You're a comical character in your own way.

David's father: Wicked sense of humour surprises me with oblique ways of looking at things from a different perspective.

On a cautionary note however, Craig's mother said

He can be very funny sometimes. But funny gets tiring when the joke's no longer funny.

About acting the buffoon Craig said

It would be boring if I didn't.' 'Dull.' Mother: 'Sometimes a bit of boring would be nice.'

Special Interests/Obsessions

Interviews revealed the degree to which special interests or obsessions impacted life and whether they had an overall negative or positive effect .

Four of the five boys spent the vast majority of their time on Playstation and Computer games. Of the four, Keith was most reflective about how his complete 'addiction' to Xbox stops him following his other hobbies. A number of times he mentioned to his father how he really wants to build something with him in the

garden. His father confirmed how before Playstation, Keith always used to
make things -

We couldn't leave any boxes Keith would take and make them into something.
He loves doing those sort of practical things unfortunately its not good for my
grass.

Keith felt he couldn't set it aside but smiled –

Unless I was paid. I'd probably set it aside.

Peter declared his obsession with everything Formula One

'I could spend the entire day on F1 and never get bored with it. Like a Maths
teacher who enjoys formulas and stuff. This stuff will stay with me till the day I
die. Everything I hear about it I remember.'

His greatest dream is to be a successful Formula One driver and he said
wistfully

If there was a F1 course I'd be in it all day every day.

His mother confirmed how this and some internet Wrestling were his only
pursuits and he had no other interests, 'not even watching TV or books'.

Craig also spends all his free time on computer games though at bedtime would
read novels, sometimes more than one at a time. His mother talked of how the
playstation got in the way of positive family time -

You can't drag him away from it.. You can drag him away to eat but that's about it

Michael demonstrated his obsession with Nintendo Pokemon games throughout
the interview when he found myriad ways of bringing the focus back to the
game he was playing as we spoke.

David was pragmatic about special interests and listed numerous -

Special Interests give you something to concentrate on. If it's something you can
develop it gives you something to work on and get better at.
Other things it's not much use having as a special Interest. I like having the fish
and the garden because I can just go out and feed them and stuff but it's not
something you can get better at.

The pond was his all absorbing special interest building project over two
summers, supported by his parents. This summer it was skateboarding –

I skateboard most at the moment but it changes a lot. Skateboarding is just something to do with the summer. I may as well go out and skate every day instead of other stuff like,,,,sleep.

Used to play a lot of Playstation but I've stopped recently because... I don't know ...well because now everyone is playing Xbox and I don't have Xbox. I don't want to get an Xbox because of how addicted I was to it. It was fun at the time but it's just a waste of time. There's nothing wrong with it an hour a day but I used to play it all day everyday.

Playstation interest waned when he was 12. His parents would not buy Xbox. Parents struggled with their sons' obsession with computer games and at the same time accepted it for what it was. The issue was raised when exploring the positive/negative balance of attention in the family –

Michael's mother: With the computer or DS it's too easy to leave him there and not make him do other things.

Keith's father: Playstation is the babysitter.

Michaels' mother: Like any child when he's good he's ignored and when he's bad he's yelled at.

Friendships

Four of the boys never socialise outside school, only venturing out with family except Craig to monthly library club and he did mention friends in school. David now socialises a lot with a large group of boy and girl friends from school and a further skating group. Two boys mentioned computer game internet friends, though these were not necessarily known outside that context. While three boys occasionally mentioned friends in school they don't have contact with them outside school. Peter avoids contact with peers at school and never mentions friends. His mother said

He hasn't had a friend for years. Apart from school he doesn't go out. He's afraid of children his own age. He likes old grannies and things because they are no threat.

Michael seemed bemused by the idea of friends-

My cousin is kind of like a friend.

His mother said he refers to a cousin whom he has not seen for 18 months as a friend.

Negative/Positive Balance

Interviews explored the balance of attention at home and elsewhere, and what gets in the way of shared positive experience. Challenging behaviour and extreme mood changes, which in turn led to parental disputes, combined to interfere with a positive home environment. As mentioned elsewhere extreme interest in computer games significantly dictated interaction in the family. Four parents described behaviour which was unco-operative, stubborn and non-compliant, often using time and energy which otherwise could be positively used. Extreme mood changes seriously affected three of the families-

Michaels' mother: The fact that you think it's all sailing fine and next minute he reacts when you're not expecting him to. Or he's crying again or he gets angry because he's crying.

Keith's father: You punching walls and throwing stuff around isn't going to help us understand.....We could be running round in circles

David's father: Sometimes it seems like there's extended periods where there is damn all to celebrate anyway. Because he's gone off on one or he's stropping for a period.

Parents clearly got distressed by the sudden switches in mood. One described how very pleasant family conversation over dinner could instantly be thrown by his inability to see another's point of view.

David's father: Its quite frankly shocking, makes me feel inadequate. I can't see it coming and I can't bring it down either when it's happened.

Another described how this set off disagreements between parents.

Michael's mother: I get caught in the middle. No. If that's what dad says then no. Sorry to say negatives get most attention. There can be quite a lot of strife around him. The downside of his clarity about what he wants to do. Means a clarity on what he doesn't want to do and that makes life difficult.

In general the extra effort needed for ordinary things got in the way –

Craig's mother: Always chasing to 'pick schoolbag up; uniform all over floor; the dishwasher is there.

Teenage hormones; mood swings constant conflict between brothers make it hard to celebrate the positive.

David's father wistfully reflected -

If time wasn't spent on the fighting....there's so many good things he could be doing and I'd enjoy that happening. Just had a thought. I wonder is it to do with spending time together.

He went on to describe the great pleasure they each got from shared tasks like burning garden waste when they spent good productive time together.

David again assumed full responsibility for not focussing on the positive –

Just me I suppose. I stand in the way sometimes. Just sometimes I'm not willing to do things that I should do so I get in the way of myself.
If I'm being negative about myself. If I don't believe in myself about something then I won't succeed in it.

Peter's mother stood in stark contrast to the other four. Her outlook on positive and negative balance had changed dramatically since his ASD diagnosis last year. She spoke at length about the transformation in her outlook, her valuing of

Peter and of the new peaceful atmosphere at home since then.-

From being a very very difficult toddler and child, he was very very difficult, a nightmare. Now I am at the stage he does my heart good.

It's only now I'm understanding his behaviour. Before he was getting told off constantly. When out he would make our life hell.

She had been advised by CAMHS team that if Peter never wanted to go out that was fine and she should just leave him to it. She described how she used to feel-

He is one of the oddest people I've ever met. He is so weird.
Why is he so difficult? Why is he so odd? Why is he so different to our daughter?

His behaviour is so bizarre. Holing himself away In his room for days on end.
Since Autism I don't lose my temper with him like I did.... 'What's wrong with you?'
I'm much easier on him. Its actually brought us closer together.

Since Craig seemed settled at school again after the trauma of second year, his mother dared to think positively about his future –

Obstacles that would have knocked him back before he takes in his stride more now. So you do start to feel a bit more positive. A few years ago I used to wonder if he would get back into school whether he would get to 5th form and come out with a single GCSE. Let alone get a degree. Although it was pretty horrible for all of us he has come out the other side stronger.

Statements

Statements of Special Educational need, and formal diagnostic assessment reports were analysed for evidence of positively focussed provision or understanding. Summaries are provided at Appendix 6.

Three boys had formal statements. Peter's report advised against progression to formal statement or provision because he was due to leave school that year and because -

most of those teachers who responded did not indicate that he was very demanding of their time, my view is he does not require additional adult support.

Peter's Mother enquired what happened about provision after he left school and the Educational Psychologist did not know. Few strength based comments were made, and occasional mentions of appearance and good behaviour during assessment.

While numerous general recommendations are made to cater for each boys' needs, very few strategies are given as to how these will be achieved. David's parents insisted reference was made to his strengths and talents in that He should be given regular opportunities to shine.

Peter's first assessment aged 6 recommended he had opportunities to experience success on a daily basis.

David's father spoke very highly of the difference his current school made to his life as recorded elsewhere in this research. His parents provided a detailed profile of him to his new school to help them understand him.

Michael's mother felt the school did value Michael-

Teachers do value him and they miss him in their classes. He's hard work too. You have to get him to shut up and get the class to get on with it.

For the most part parents could not find evidence of the school or other services working to highlight and support the positive in their son.

Peter's mother: I've had very little positive apart from one teacher. She said 'He doesn't create trouble in classroom..' He's very compliant, very polite, very well mannered' That's the only positive. She allows him to go into her room at lunch and break-times.

Craig's mother: We don't get any support. Any services are there it's the medical side. What are the problems? What if anything can be done to support you with these problems?.

There is no doubt he is very gifted academically and grammar is academically geared. I suppose in that's sense he's encouraged to achieve his potential.

School's only interested in terms of meeting curriculum. He wouldn't be treated any differently to any other pupil. Parent evenings discuss what he's doing well. Teachers have a common Voice –

Organize your work a bit better and hand in your homeworks. Don't sit looking out the window if it's something you are not interested in.

Three parents specifically mentioned the statement and one was pleased with the amount of detail provided. The others were not.

Craig's mother: For all the effort that went in the actual statement is so short and so vague - did we really have to jump through all those hoops..... all the statement is is a rehash of what everybody has said. I was expecting something more specific and it was just a rehash.

Peter's mother: You don't even understand half the stuff written in it. It's gobbledegook.

Craig's mother said how his IQ had tested at around 133 and probably higher as anxiety had prevented him working at speed. He said -

I'd like to get it re-tested. Mother replied: I think it would make your head too big.

Autism Quotient Adolescent Questionnaire

Parents completed an AQ (Baron-Cohen et al 2006) as supplementary data to inform the interview data and documentary evidence. The AQ measures the degree to which an individual adolescent shows autistic traits on 5 dimensions - social, communication, imagination, attention to detail, and attention switching.

The AQ assumes a cut off score of 30 to differentiate matched controls and Asperger syndrome/High functioning Autism. The AQ is not a diagnostic tool and future work is needed to examine any relationship between individual scores and severity of symptoms. Raw scores suggested that Peter, David Michael and Keith all fell in the AS/HFA range, Craig scored well below at 24, attention to detail and poor imagination being the traits he demonstrated least –

Autism Quotient (AQ)	Craig	David	Peter	Michael	Keith
	Total	Total	Total	Total	Total
	24	36	43	33	42
Poor Social Skill	6	6	10	8	10
Poor Attention switching /strong focus of attention	7	9	10	4	9
Exceptional Attention to detail	3	4	5	6	8
Poor Communications	7	10	8	9	9
Poor Imagination	1	7	10	6	6

Craig's mother was the only parent who questioned the AS diagnosis. She could not reconcile Craig's extremes of emotion with her understanding of the 'classic definition.' She could not find retrospective evidence from his early childhood that fitted the definition and questioned 'where does Aspergers start and teenager end?' All in all she was unhappy with the accuracy of tests run, because of Craig's 'obstinate and argumentative' mood at the time and had hoped for a more specific report. Craig's IQ was 133. IQ scores above 130 are considered gifted.

Professional Services

During the interviews professionals like CAMHS (Child and Adolescent Mental health Service) and Education Authorities were mentioned at various times. The experiences were widely varied. The three 15 year olds all had experience of CAMHS.

David

The parents initially sought help and were referred to CAMHS via the GP, and this team led his diagnosis. Quarterly review meetings. Seemed 'pointless' and the family discharged themselves during 2nd Year. The family called in social services when he threatened self harm in first year and a social worker reviews

him twice a year, and accessed a behavioural support buddy for him for a year. No other comment on any professional input or involvement arose during his interview.

Peter

Peter had a GP referral to CAMHS after he became depressed. His mother reported

He started seeing CAMHS. Became depressed. Looking out window he'd say 'There is nothing out there for me.' There's no point in me being here.

After some months the CAMHS doctor suggested Peter might be Autistic and he was later diagnosed ASD. In regard to his learning difficulties diagnosed aged 7 it reported that 'Autism had been masked by learning difficulties all these years'.

Peter clearly appreciated his relationship with the CAMHS doctor –

Dr X took away a lot of my fears, of other people like. He took away a good chunk. It's more like a counselling service now. It's good it's relaxing. I enjoy going.

Mother: The doctor at CAMHS has provided more positive than anyone else. He seems to have got inside his head and he is really intrigued by him. He really likes him.

Peter's mum spoke a lot about how massive a change had been brought about by Peter's diagnosis the previous year. She found the CAMHS advice invaluable –

They said 'If he doesn't want to go out don't force him, just leave him.' So instead of getting into these battles with him, everyone's happier.' I'm so much more laid back now. If he doesn't want to go out that's fine. See you later.

Nonetheless, the Interview did reveal how depressed Peter was feeling. He had described his feelings in his private interview when asked to consider the future and the researcher drew back to that when later, Peter and his mother were sharing the experience. Peter had very thoughtfully said

A lot of time I do feel miserable. I do suffer from depression. It's just called reality what I'm going through in my life. Going through school it's been hard for me. It's taught me what life is going to be like, because I have been treated very unfairly. I learned to adapt to and realise life isn't fair and take the mature approach to it.

It's just the way the cards fall. I have to deal with it and look at the positive side of it.

During the years of bullying I was treated unfairly a lot by people so I've learned how to adapt to situations. I've moved on myself.

Peter and his mother later agreed that they would need to bring the issue to Dr. X at CAMHS. He insisted that 'it's probably something I need to deal with myself.'

Craig

Craig had described how he wanted to be a counsellor or psychologist in the future, and without asking went on to describe his experience with CAMHS.

which he visits for regular reviews -

It's either 'take this medication' or 'tell me how you feel.' They don't do much to help to be honest. I don't really see how it helps.

xxxx is worse to be honest. They just keep asking questions. All just negative negative negative. Makes me feel inferior. Different. It says You are inferior so how do you feel about that?

I would like to tell them - 'Stop treating me like I'm some sort of disabled person.' It's like they're asking what kind of wheelchair I would like.

He went on to describe his stay as an inpatient

This completely awful feeling. You feel like you just want to stop bothering. It's not something that could be understood if you haven't felt it.

You're away from your family and friends. It's kind of ironic to be there to help keep people sane but a lot of people probably go even crazier. A lot of people who were there when I went in by the time I was leaving didn't seem better.

Basically the strategy is to just shut up, do what they tell you and pretend to be improving, I guess, just to get out of there.

Mother: To be allowed to go home.

His mother later described his reluctance to take even a painkiller following the experience which he described

'the paranoia of Mental Health Service stereotyped in my head. All the people there trying to put drugs in you and stuff.'

Mother: This is why you could be a psychologist or a counsellor 'cos you could do a different job.

They said nothing more about the experience.

Keith

Keith's father had described his own long and painful experience with Mental Health Services and his own recent AS diagnosis. He also spoke of the struggle to have his first son diagnosed and cared for early in secondary school, followed by his current 'fight' with Education and Health for an accepted diagnosis and statement for Keith –

As with all professionals- GPs; ed. Psychs. etc. they don't know what you're talking about. Because we don't have a phd or masters or something they think 'we know better than you.' And they don't, they really don't. I tell them I give talks about it and give training on it and to top it off have Autism myself. Fact is I probably know more than you ever will. That wasn't getting digs at them. These were my credentials.

You get nodding heads. Nothing we've asked has ever been put into place. It's like they all close in against you. All those professionals in the trust. Social services would be the same. 'Well we say he hasn't got it (Asperger's Syndrome) so we are not backing you up.'

Keith had no experience of CAMHS and only a short one hour statutory assessment for AS, but had also experienced a full days' assessment by a private education psychologist, and also attended her for sessions on a regular basis. He was clearly perplexed by the forthcoming educational tribunal

How can there be a 64 page report that says I have got it rather than just a sentence that says 'I have got it?'

Asked who supported him he mentioned the support his mother provides in preparing for the tribunal. His father was keen to point up the support Keith got from the private psychologist.

Future Hopes

All the boys struggled to imagine the future beyond an occupation. Keith and Michael want to be inventors; Peter a mechanic; Craig a counsellor or psychologist and to 'make a difference'. David was troubled about what to do after school and how to get a job. He didn't relish getting older-

You don't really have a life when you get older.
You don't want to be doing the one thing for the rest of your life.

Regardless of whether it was stacking shelves at Tesco; a fitter at Shorts or some professional job, the parents presented some common attributes. A condition of some was that the job was one which interested their son –

Follows instructions.....	Precisely, to the 'letter of the law.'
Keeps Rules	Sticks at a task.
Hard Working/Focussed.	Puts All energy into the job.
If interested will be keen to expand knowledge.	Will observe rules like break-times
'On The Ball'.	Precision on task.

They added some caveats –

He will need more and detailed training and instructions. He will not be good for social relating and 'banter.'

Aware of how his Autism and learning difficulties would limit Peter's options his mother said with determination -

He is going to stack shelves in Tesco or something. He won't just sit on the dole. He will go out and add to society. I'll make sure he does.

Most parents expressed their wish for their boy's happiness above all else and that they would find a life partner. One mother revealed her own life struggle.

Her husband has not had an Asperger diagnosis -

I hope if that's what he really wants someday he'll find someone willing to take him on with his idiosyncracies. Someone who he'll be there for them. He'll be loving and caring and....he'll be stuck in the computer. He'll not give that person the support that they probably deserve .
He'll probably not give that person support but he might love them with all his heart. Hell need to find someone who can live with that. I live with it.

Understanding the ASD Diagnosis

All of the boys had a very limited understanding of what Autistic Spectrum Disorders or Asperger Syndrome meant. They were mostly not interested in taking part in a group to learn more about what ASD might mean.

Craig felt very uncomfortable with the label, or the condition. Asked how he described that he said –

different just different I guess. Not like normal.

I know everybody's different but I'm just more different. It just tells me I'm at a disadvantage, like socially. It feels like a morale dropper.

Keith said it mattered that people called it a disability however thought a disability could be used in different ways. He then asked-

So is calling it disability a good thing or a bad thing?

Peter was clear that ASD was no disability for him though perhaps it caused some 'social difficulty'. He felt it was like a learning difficulty where 'you struggle with things'. About diagnosis he said –

I've lived most of my life without it. so it makes no real difference.

David didn't think the label had much relevance in his life now and thought too much attention was paid to it -

It's a bit annoying sometimes because I think people pay too much attention to it. Most people don't even know actually but you guys and school they do get too uptight about it. Its just part of my personality I think.

He also believed he had developed a lot –

A few years ago It used to be more clear that I had Aspergers. I just behaved like it. Weirdly. I was more odd. Yeah I didn't know how to socialize as well, didn't really have many friends.' I think I've moved on like quite a lot. I didn't have social difficulties I just didn't have many friends. I had a few friends though.

About the meaning of the label –

Its supposed to mean I'm not as functional in society or something like that....but F that.

Some people are completely affected by it. Like some people can't just function. They don't understand what people are...they don't understand something unless it's completely logical. Some people wouldn't even see the point in entertainment. It just makes people really boring sometimes. If they're like that they have bad autism or Aspergers.

The Interview Process

It is fair to say that all participants, young person and parent, found it hard to explore and verbalise their positive experience of life with ASD. There was a tendency always to tell the story of the challenges, the difficulties and the life journey so far.

None remembered being asked anywhere else to focus on the positive.

Staying with the struggle to emphasise the positive throughout the data gathering interviews generated new insight and in some cases hope for some –

Peter's mother: Its first time I've ever been asked to think in positive. Its always the negative points being brought out by healthcare professionals, teachers and all, shortcomings and all the negative stuff. How that effects their lives and other peoples lives. I find it hard to think.

After this I'll be able to put an even more positive stance on it. I'll be careful now about how I'm talking about him. I'll be emphasising the positive rather than what I have for years and years.

It's been enlightening now since that diagnosis. And now with this I'll be even more positive again.

You've made me think. There are many more positives to this than I had ever thought. That's because of this interview.

Craig's mother: It's making me think about how I look at things. How we concentrate on the negative. It forces you to focus on the opposite side of any conversation I've ever had. Mostly it's about the negative and what the problems are and how you are going to tackle those problems. 'I think the good does get lost.

Both David and Keith's fathers earlier declared they too had Asperger syndrome. David's dad found the interview difficult in a way that perhaps reflected his own ASD –

I found it very difficult, really really hard. All this stuff dredging into what you think or feel about people. I find it enormously energetically draining. I'd feel fresher after a days gardening. I don't think like this very often. I usually have a very specific task to do or problem to fix.

Reflecting further -

It's good to consider the positives. It's too easy to focus on the negatives. That tends to be my approach to focus on the negatives and fix them, Maybe that's an insight. I'm a fixer.

Keith's dad had revealed how in his school days 'you were either mad or bad.'
He had said a lot about his struggle to get school and professionals to listen.

About this interview –

I'm glad somebody's taking an interest and somebody listening who does understand. It's good to have someone interested, and willing to listen.

Asked if he'd found out anything new he felt he hadn't as he knew his son very well. He was however quickly corrected by Keith.

No you don't.

This short interchange led them into a discussion about Keith's need to have his parents listen to him more. Asked what it was like discussing himself in the interview he said –

I liked talking about things people don't know about me.

Four of the young people readily participated and reflected though all struggled to speak positively about themselves-

David: 'It's very boring. I find it really really hard work. I don't enjoy it. It's hard to get answers out of nowhere. Its not concrete. It's hard to say good things about yourself. It would be easier to talk about other people.'

Craig: That's been very helpful thanks. It's just made me think about things a bit more '

Peter: I don't know. I can think more of the bad stuff than I can about the good stuff'.

Michael was more engaged with his Nintendo Game throughout the interview, and matter of factly answered without seeming to reflect. Asked what it was like to hear his mother speak very highly of him Michael said

Doesn't everyone's parents? Nightnight.

He then left the room!

DISCUSSION

This project explicitly sought to enable participants to focus on their inherent positive value, and create positive dialogue between child and parent. Of more than 1000 books now written on ASD a very few now set out to celebrate the positive (Boyd 2009, Jackson 2002, Ledgin 2003,). Others however, (Ortiz 2008, Lyons and Fitzgerald 2005) tended towards revealing the exceptional individual talents personalities and gifts of genius and savant figures from history and today, life stories far removed from the ordinary everyday person with ASD. This project became a quest to free that voice as results revealed the almost complete absence of any reference to the positive by schools, professional bodies, diagnostic consultants and so, the families themselves.

Much literature and professional experience is committed to evaluating the deficit; disability and difficulties, and seeks to describe interventions and strategies to 'treat' those conditions. In this light, we can better support the dissatisfaction of Molloy and Vassil (2004) with a 'medical model' of diagnosis and labelling. By its very nature a diagnosis seeks to find and elucidate the disorder and dis - ability. Furthermore Farrugia and Hudson(2006) called for better diagnosis and treatment of co-morbid conditions as a response to the significant prevalence of anxiety among young people with ASD – an entirely medical response. Fortunately Baron-Cohen challenged the negative approach which majors on the inability to empathise, by emphasising systemizing abilities which lead to great careers in maths, sciences, and engineering (Baron-Cohen 2002, 2004). Happe's research (2008) also challenged the weak central coherence focus to be instead judged an exceptional a - bility to focus on small detailed parts of a whole, again a skill much required in many analytical spheres. The discussion now compares and contrasts the key challenges of living positively with a diagnosis of ASD, with the literature, and makes recommendations for schools and families.

The Impact of School

School has been the dominant experience in the lives of four of the boys, all the more so because they do not socialise outside school and have few if any friends. This was also true of David until his last change of school at the end of 3rd year. Craig and Peter were not diagnosed ASD until severe difficulties in secondary school occurred, and Peter not until 5th year. The results showed –

- Craig had a complete mental breakdown resulting in his exclusion from Grammar school and a four month stay in a residential child and family unit.
- Peter was traumatised through bullying experience and moved schools with remaining severe anxiety around young people.
- David self-harmed and remained socially isolated and experienced poor school-home communications, thus became unable to continue at his first grammar school.
- Keith finished first year in continuous, sometimes physical battle with teachers and peers, and in receipt of many detentions whilst awaiting outcome of a tribunal to determine his diagnosis of AS and any potential support.
- Michael suspended twice in first year.

Students with ASD are 20 times more likely to be excluded from school (Barnard et al 2000).

School dominated interviews and literature and influenced the whole spectrum of challenges including self esteem, appearing normal; anxiety, bullying friendship, mental health and living with ASD. Schools normally measure pupils on academic achievement and an ability to conform but what is schools' responsibility in shaping the whole life of young people with ASD?

Jordan (2008) explicitly defines education as the way in which 'values, understanding, knowledge and skills' are taught. and results show how education greatly influences the 'gateway' to full social inclusion and should enable full participation in the community. She recommends a system that is flexible –and which cannot rely on centrally determined curricula and teaching

methodologies. Keith and David both loved art yet Keith did not believe his art teacher even knew he was talented in this. David, assessed as 'exceptionally talented' in art, felt very frustrated following a rigid year long art project, An alternative pathway to GCSE hadn't been considered, and David was determined to quit the very subject where he could demonstrate talent and ability that would enhance friendships, peer respect and academic achievement. Keith's private writings were profoundly moving, but he was assessed below average in English. David, published in a national young person's book hated English above all subjects.

English definitely. I can already speak the language I don't need to study Dancing at Lughnasa and all.

Coincidentally his Spoken language score was at 98th centile when tested aged 8. This is accepted as a key predictor of positive outcomes for ASD.

Craig spoke proudly about primary school where he was encouraged to read books aloud to the class and narrated school plays. He read fluently from a very young age. However, there is no reference to this talent in statements or school reports. Feedback given by school was all about what Craig had to do better in order to achieve good marks.

Jordan (2008) acknowledged the challenge for teachers working within the system and the fact that it is simply hard to teach pupils with ASD, for the same reasons as pupils find it hard: they cannot intuitively understand what is wanted and needed, having to rely on cognitive piece by piece interactions to grasp meaning. Social instincts cannot be relied on and so it is indeed equally laborious for teachers who have to consciously work at how to respond to the ASD needs. Statements (Appendix 6) did not guide teachers' attitude and behaviour and relied on general recommendations to 'Help Craig to...' or 'Clarify' or 'develop' or 'promote'. Perhaps specific behavioural guidance would enable teachers to translate objectives into practice. Chape (2009) herself a teacher, called for extensive teacher training in ASD along with research to identify effective interventions for teaching ASD in a mainstream school. She sympathised with the confusion for regular teachers. Jordan (2008) called for teachers to display 'informed empathy' thus developing their own emotional

literacy as much as expecting to develop it in the children. The same skills might help teachers understand the function of behaviour deemed inappropriate, which Cumine recommends should be done 'from the point of view of the child' (Cumine et al 1998 p.54).

Negative/ Positive?

Gifted students experience similar difficulties in social and communication skills as those with ASD. Gifted students with AS need a 'dually differentiated' curriculum that will work with the full range of students abilities and limitations (Baum, Cooper and Neu 2001), but programmes often fail to identify or meet needs particularly those students known as 'double-labelled and 'challengings'. Though detailed positive guidance is given (NCCA 2007) failure remains the focus. OAASIS also focus on nurturing strengths (Gething 2003). Statements and assessment reports (Appendix 6), showed only two unspecific references to the need to focus on learning strengths, one of which was insisted on by David's parents. Occasional references were made to Craig's exceptional ability, and Peter's visual learning strength and an independent psychology report recommended a differentiated curriculum for Keith. No guidance was provided to meet those needs. Parents could not recall any positive reinforcement, except for standard parent evening comments about Craig's performance.

Strength-Based learning

Students with AS desperately want to have their special interests and passions included in school work and research showed social communication and fine motor skills improved when this happened. (Winter-Messiehs 2007) He confirmed the researchers' own view that the restricted emphasis on remedying problems over attending to gifts and talents was particularly frustrating for those who desperately need challenges and opportunities to demonstrate their knowledge. Craig revealed this frustration as he scorned those peers of lesser intelligence who also tended to laugh at him, mocking their use of English and

intelligence, and was keen to prove his higher IQ by being retested. Craig's mum knew of no evidence of the school making efforts to work with his 'academic giftedness' beyond the normal grammar school curriculum. Winter-Messiehs (2007) pointed to the need to provide educational programmes in a stimulating learning environment and provide active enquiry and interdisciplinary thematic instruction, mentoring and using the student's passion to develop academic and social skills together. Authentic learning was also mentioned, best described through the home experience of David's all encompassing passion of fish ponds. His father described how his pleading for a pond was granted on the basis that he researched the internet for all technical aspects of build, cost, design, fish stocks, filtration etc. He also had to lead on the physical work involved, and do chores to earn money to contribute to costs, which he would calculate. His father explained how the project provided a way for him to build his I.T. and maths skill, took him away from the computer games and provided an enormous sense of achievement.

Peter, passionate about formula one racing, had commented how if he could do a course in the subject he would attend every day, despite hating school.

Through the research process the boys managed to overcome difficulties with finding anything positive to say about themselves and revealed numerous areas of talent. Peter, Craig, and Keith all mentioned their powerful memory and their ability to absorb information without effort. Who is to say any or all of the boys could not make enormous strides given an opportunity to be treated as gifted? Young people with ASD experience significantly more depression and low self-esteem (Howlin, 2003, p.20). Authors with ASD reported their need for positive input in order to boost the 'self esteem which flounders so easily' (Lawson, 2003, p.40). Unrecognized Idiosyncratic social skills lead to aggressive behaviour at transition to secondary school (Simpson and Myles, 1998). Yet education does not enquire or attend to strengths, passions and interests of children. Teachers who are largely supportive of inclusion struggle due to low confidence and lack of training (Chape, 2009). Jordan's (2008) plea is for government to allow teachers to act as professionals not technicians and to 'allow people to develop their talents rather than concentrating on their

difficulties' (Jordan 2008 p.18). School guidance for special needs including ASD before statementing stage, includes more than 60 positive strategies (DENI 2009) but what prevents their implementation?

An organization development perspective on 'resistance to change' suggests that systems must make changes impossible to ignore, by tying success to Annual performance reviews, personal development plans and pay and reward. (Bellanca,R. 2007) In other words, perhaps only when teachers pay and rewards, and school funding, are tied to qualitative measures of inclusion efforts, will we see education embracing special needs.

Bullying

All the boys in this study experienced bullying and for some, this was extreme. Peter visually and emotionally described the scar he was left with as a result, along with his sense that no-one appreciated just how bad this was. Craig bore the marks from an assault in the playground. The literature had revealed the serious issue of bullying of children with ASD in Northern Ireland, and noted the perceptual gap between the children's experiences and schools' reports, which never mentioned bullying as an issue. This gap was reflected in the results. Psychology reports into Craig's severe mental health breakdown revealed the same gap. Of his reports of bullying by peers and older students it states '...when investigated appeared to have little or no foundation.' His mother felt they still had to cope with the underlying assumption that he was the one out of step or at fault and she was almost relieved he had cuts to prove the incident in the playground had in fact happened.

In Peter's case, he stayed away from all his peers in his current school due to the earlier bullying. His mother also reported some less serious bullying in his present school. School dealt with this by allowing him to stay in a classroom, alone, during breaks, an arrangement for which his mother was grateful. No enquiry was made.

Michael's bullying happened mostly in the shared taxi school taxi. However, because this was off school property, the school did not intervene and his

mother couldn't influence the situation. Whether or not hard evidence can be found of bullying in school, the boys' experience was very real and caused physical and emotional. Incidentally, DfES guidance on bullying due to race, gender, and sexuality focuses on strategies for changing the bully behaviour. By comparison strategies for learning disability bullying focus on helping the bullied pupil deal with it (NAS 2006). Working with the student's perception is the starting point to understanding the child's perspective.

Appearing normal

Where do parents draw the line in seeking conformity from the child around the myriad everyday challenges? Advocates like Williams (1996), Moyes (2003) and Lasser and Corley (2008) warned of efforts to fix or fundamentally change the child, possibly driven by the parents need for the child to fit in. Attwood's internalising or externalising coping strategies adopted by young people to appear normal and fit in (Attwood 2006), gave useful insights into the complexity of the boys in this study -

David seemed to cope by avoiding the label, striving to learn as much as possible to appear normal. This included his privately motivated work on physical coordination. 'Starting free-running helped my coordination and stuff and allowed me to do other physical activity and things 'cos I wasn't very good at that kind of thing.' His fighting behaviour at family times and deep sensitivity to perceived criticism may have reflected his extroverted coping, yet he also often expressed a deep sense of responsibility for his condition; for the first grammar school failure; and for what blocked him being positive, as if it was all his fault.

Craig felt labelled and excluded and was keenly sensitive and angry with peers and professionals. He seemed desperate to appear normal and thwarted by continuing bullying by peers. He appeared to cope by proving his superior intelligence to peers and family, being witty and adopting a caring sympathetic

attitude. He presented a very sensible, grown up persona, and seemed conscious to avoid letting any 'negative' emotion be seen, though it leaked through numerous times. At one point his deep anger at those who mocked him came out full force –

I hope they enjoy their lung cancer after smoking behind the Maths block.
Most of them are jerks. Its like ' MY friends laughing at him so Ill just laugh as well.'

I don't like people who just like what their friends like, racists, shallow minded people or who waste all their money on gold jewellery etc. who get into debt. Celebrity people, who go and waste their money. People who are like idiots to be honest.

His mother confirmed the 'inner' Craig who was sensitive, emotional and a 'big softie.'

Peter had learned to cope by shutting himself off from the world, spending the vast majority of his time in his bedroom on formula one pursuits. His seemed to be an entirely internalized response. He talked about his depression and emotional scarring and before his referral to CAMHS his mum confirmed him saying 'There's nothing out there for me, There's no point in me being here.' He did not convey any sense of that changing or of blaming anyone, and said 'its just how the cards fall.' Peter's mother, whose outlook changed dramatically after his recent diagnosis now felt able to leave Peter to his isolation rather than continue to force him out.

Attwood warned of the dangers of suicidal talk for such boys. These concerns were heightened during the interviews. The client centred approach at interview enabled the researcher to raise the depression with mother and son and they agreed to take it to CAMHS. His mother was hitherto unaware of Peter's current depressions and concerns.

Keith seemed to cope by fighting the world and so seemed to externalize. He reported numerous physical fights in school and spent a good deal of the interview time arguing with his father as if trying to antagonise him. His father confirmed a lot of arguing at home. At one such moment in the interview the researcher asked in a light-hearted way 'do you enjoy fighting and arguing?' He

laughed, and said 'yes!' Like David however he too internalized his experience through his profound private writing.

Just someone help me right now.
Just help me, I need help.
I'm just really upset, I need a friend, I want attention.
I just need help, why doesn't anyone help me, I just need answers. It's always been no. I just want people to understand me.
I'm just feeling I'm wasting my time, hardly eating. I need help.

Clearly any person intervening or teaching would need to be able to get past the exterior 'facade' to reach the sensitive, reflective boys beneath.

Michael, fully absorbed in his Pokemon game world seemed to react moment by moment to life. While he did mention bullying he did not seem to dwell on negative or positive, simply responding to life as presented. He was only superficially aware of his condition - 'it means I'm just as equal as everybody else.' If anything, Michael might be considered as disappearing into fantasy world of Pokemon. His desire to be an inventor when he grows up was Pokemon based and he wanted to invent a machine to take him to Pokemon world. Attwood warned of the contrast between real and fantasy worlds becoming extreme with the person retreating into fantasy to the exclusion of other important activities(Attwood 2007 p.187).

It seemed the parents instinctively drew their own line in coping, and knew both the externalizing and internalizing behaviour of the boys. Peter's mother of course stood out for her shift in perception, and behaviour towards Peter upon diagnosis, letting go of pushing him to socialize. David's parents sought his conformity by breaking through his computer game obsession. Attwood's framework provided a useful way to make sense of the behaviour and motivation of the boys.

Special Interests

The very isolated, intensive pursuit of computer games by the four boys gave much sharper focus to the question around how much parents need seek conformity to neurotypical behaviour. Jackson (2002), himself very committed to

computer games, was clear in advising parents to leave alone unless the pursuit was dangerous or risked a negative effect on the child. Williams also wrote persuasively about the real damage to her person when adults failed to accept her autism. Findings reported here challenge the idea that respecting the condition and the individuality of the child necessarily means 'leaving well alone' or setting no limits on isolating, fantasy based computer gaming. Four boys spent the vast majority of non-school time alone, on computer games, and this was true for David until parents refused to buy Xbox, and diverted his energies into his interest in fishponds. Evidence showed that obsessive special interest caused friction and disputes in three of the homes but parents seemed understandably caught in the bind of welcoming the peace and quiet when the boys were absorbed, and resistance and arguing when parents called a halt. Parents had also spoken wearily of the amount of effort needed just to get through the day with the considerable extra demands placed by having a son with ASD. Keith was very creative before Xbox, and wanted his father to work creatively with him in the garden. David unprompted also mentioned how he was pleased to not 'waste' his time on gaming. It is possible that the commitment to computer games drove the boys' social isolation and lack of friendships. In any case the results suggested it did not help social integration. Asperger suggested that as a coping strategy, special interests provided the platform for the child's strengths and social integration. He however did not live in the age of computer games. Perhaps the interest could be diverted into computer games designed specifically to teach social skills in a virtual world like 'Second Life' (1999). However, experts have warned of the danger of an environment so comfortable that pupils with ASD may never want to move beyond it, and numerous computer blogs spell out the devastating consequences of the game.

Adolescent compulsive computer use studied by Vancott (2007) suggested the question became valid only when excessive use caused significant problems for the user or family and affected the ability to function in the real world. Key symptoms included loss of sense of time or neglect; withdrawal with feelings of anger tension or depression, tolerance increasing need for more hours use,

more equipment etc., and negative repercussions, including arguments, social isolation and fatigue. Given that young people with ASD are very likely to experience the above symptoms anyway, it seems parents would be best advised to find some way to face the conflict while sensitively managing a reduction in the boys play time. Peter and his mother discussed how his recent helping in the garden was very positive and perhaps that was a diversionary route for him. Keith's plea for a shared garden construction project might provide enough of a lever to overcome the financial challenge of his father for setting Xbox aside.

The Interview Process

Results highlighted numerous occasions where the interview process allowed intimacy and understanding to emerge between parent and child. The positive value of this alone cannot be underestimated. Most striking was when Keith and his father, who seem to spar with each other a lot, reached an important point of understanding. The excerpt summarises an approach that allowed a developing theory of mind between them, and way forward in dealing with the regular conflict from broken communications at home. After an impasse following some disagreement between Keith and his father -

Researcher: You want your Dad to say what's really good about you but when he does you tell him he's not saying what you want to hear. What is it that you really want your Mum and Dad to say to you that's' really good stuff?

Keith: I don't know, he's supposed to know that.

Father: No. I can't know unless you tell me.....The things that you say inside your head, people can't understand because you're not telling them. You get frustrated and angry because it's not working your way.

Keith: It never works my way.

Researcher: Maybe If Dad's not telling you what you need to hear then you need to tell him that?

Long pause.

Researcher: Or is it just 'You know what, I'm really special and there's so much about me that you don't know and I want you to know?'

Keith quietly : She just said it.

Father: Your mum says I can't help you if you don't tell me what is wrong. You punching walls and throwing things about doesn't give us an answer. You have to tell us because we could be running round in circles trying to work out what the problem is.

We went on to discuss how Keith could just say 'Help' and based on his interest in flags he could use his white flag to let them know when he needed help. Later Keith told his father he really wanted him to know 'I'm not an idiot. I'm not always hyper.' 'Help me more.'

The key to the growing understanding between parents and boys was empathy. Greenspan realized that only when autistic people understood their own emotions, could they consider themselves, or anyone else, and make the intuitive leap to another's world (Greenspan 2008). Tutt suggested empathy is dependant on an awareness of self and at the heart of an ability to socialise (Tutt et al 2006). Rogers proved how it is almost impossible to remain alienated when being offered profound understanding at a very personal level (Rogers 1990). Empathic understanding skill could greatly benefit parents, teachers and professionals.

Outcomes

David appears to have made significant developmental advances against key diagnostic criteria, against a background of self-harming, two secondary school changes and socially isolated childhood -

Qualitative Impairment in Social Interaction : Now very socially active with a solid group of friends from school and a skateboarding friendship group and has had girlfriends. No social difficulties reported from school. Aware of past without friends and own social difficulties. Increasingly socially appropriate.

Restricted interests and Activities : Very aware of extending his interests and their benefit to him, Aware of earlier computer game obsession. Past disturbance did pervade life.

Language delay : Strong language skills, verbal and written. 96th centile for verbal ability yet still experiencing communication and self organizational difficulties leading to temper outbursts and family arguments (a high number on the Autism Quotient).

Motor clumsiness : Dominated life until aged 12/13. Self determined regime to develop physical coordination and skills.

Further research could usefully study that developmental path with a view to identifying leading factors, and compare those to the paths of the other four boys. For now we might conclude that his current school and statement is providing all the necessary supports to enable him to flourish and develop; the determined effort by his parents to divert him from obsessive computer game pastime, and his own sense of personal responsibility. It is questionable whether David would meet diagnostic criteria today by not presenting obvious clinical signs of distress, though his AQ revealed high communication scores. We can only wonder what difference early diagnosis and intervention would have had on Peter's development and happiness, who first came to the authorities attention aged 3.

Understanding Diagnosis

It was clear that none of the boys understood their diagnosis, and most particularly its positive dimensions. Neither did they have opportunity to talk about what it meant to them; only Peter's views were sought in the writing of his assessment. While only one boy was keen to have a focus workshop, all had moments of surprise as they discovered a talent, like working memory, which could be aligned to ASD. Results support Murray (2006) who stressed the need to unfold an understanding of the diagnosis based on the living reality of the person at the time. Whilst Attwood's preferred 'Congratulations', is laudible in its intent, results show young people receiving a confusing negative message from which they judge their place in society(Attwood 2006, p 332).

Conclusion

The study revealed the profound lack of positive enquiry or intervention to express strengths or meet young peoples' needs as they valiantly strive to function in mainstream. Their voices were rarely sought by education or support professionals, despite common experiences of bullying, low self esteem and mental health issues. Most families remained alone to deal with the many social and communication challenges of adolescence and school, all the time unaware of their own talents and strengths. The study evidenced just how much insight young people with ASD have to inform those responsible for their development.

School was the dominant social influence in the lives of the boys. The study therefore questions the role schools must take in shaping the curriculum to the social and communication challenges of children, with a focus on individual strengths and passions. Education psychology and clinical diagnosticians equally can benefit by amending their processes to include the positive voice of both child and parent.

Empathic understanding provided conditions allowing the boys and parents to open in awareness and in appreciation of themselves. It was moving and inspiring to witness the growing intimacy between child and parent, and enabled self reflection and a developing theory of mind between them.

Recommendations

For Schools

Provide much needed training in ASD for teachers striving to meet many disparate needs in one classroom.

- Train teachers, professionals parents and people with ASD in empathic understanding and begin to provide a 'medical model' antidote.
- Include student in defining their support needs as a valuable source of information and guidance.(Billington 2006).
- Follow the key questions recommended for gifted students (Bianco et al)
 - What are students interests and passions?
 - What are students learning strengths?

- How can I use his or her strengths to teach academic and social skills?
- What are some real life problems in his interest area that my student could usefully explore?
- What might authentic learning and authentic assessment look like for my student?
- How can I build an interdisciplinary thematic unit around his special interests and learning strengths?
- What resources (print, film, community, internet) can we access?
- What local national or international experts can be used as potential mentors?

Future Research

- Further research could usefully compare the treatment of gifted or twice exceptional students, and those with ASD, measuring outcomes of equal treatment.
- Research comparative outcomes for participants. David stood out for his enormous development, and happiness in recent years. A follow up study in 2 or 5 years time would reveal the development milestones for all the boys as they transitioned through the school system.
- Research an intervention replacing computer game use with other key interests or strengths and measure outcomes.

For Parents and Young people

- Design and run the 'positive voice' workshops as initially hoped in this project.
- Teach parents how to write personal statements for ASD schoolchildren to inform school understanding of personality, needs talent and passions.
- Offer regular workshops for young people on understanding diagnosis, in context of their real life issues at the time.

Ensure the diagnostic process includes the child's voice focussing on Needs, Strengths and Passions.

Reflective Learning

The experience confirmed the emphasis of my coaching and counselling work with families – empathic understanding, and I recognize it as a valuable intervention in its own right, possibly the keystone for any other work. Working with parents and teenagers confirmed the great struggle parents have, to understand and adapt to their sons, and the effort involved. Even with my own personal experience as a mother, it still somewhat surprised me, and I realise the great need for support for parents in terms of training, listening and guidance. Further, when parents find the road so tough I can better appreciate the real difficulty for teachers who do not have the time or training to enable deeper understanding of the children they serve. While I already knew my own personal struggles to stay positive I was surprised at just how challenging the search was for participants and their difficulty discussing ASD with their children. However the moments of understanding and intimacy between child and parent during interviews, and the growing sense of self worth in the boys confirmed the value and importance of striving to uncover and appreciate the positive.

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APPENDICES

APPENDIX 1 Attributes List (Attwood 2006 p331)

APPENDIX 2 Gillberg's Criteria For Aspergers Syndrome

APPENDIX 3 DSM-IV-R Diagnostic Criteria

APPENDIX 4 Research Participant Details

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APPENDIX 1 Attributes List (Attwood 2006 p331)

Qualities

Honest
Determined
An expert on insects the Titanic
etc.
Aware of sounds others can't
hear
Kind
Forthright
A loner(and happy to be so)
A perfectionist
A reliable friend
Good at drawing
Observant of details others do
not see
Exceptional at remembering
things that other people have
forgotten
Humorous in a unique way
Advanced in knowledge of
mathematics
Liked by adults

Difficulties

Accepting mistakes
Making Friends
Taking advice
Managing my anger
Handwriting
Knowing what someone is
thinking
Avoiding being teased
Showing as much affection as
other family members expect
Tolerating specific sounds
Explaining thoughts using
speech
Coping with surprises

APPENDIX 2 Gillberg's Criteria For Aspergers Syndrome

1. Severe impairment in reciprocal social interaction

(at least two of the following)

- (a) inability to interact with peers*
- (b) lack of desire to interact with peers*
- (c) lack of appreciation of social cues*
- (d) socially and emotionally inappropriate behavior*

2. All-absorbing narrow interest

(at least one of the following)

- (a) exclusion of other activities*
- (b) repetitive adherence*
- (c) more rote than meaning*

3. Imposition of routines and interests

(at least one of the following)

- (a) on self, in aspects of life and (b) on others*

4. Speech and language problems

(at least three of the following)

- (a) delayed development*
- (b) superficially perfect expressive language*
- (c) formal, pedantic language*
- (d) odd prosody, peculiar voice characteristics*
- (e) impairment of comprehension including misinterpretations of literal/implied meanings*

5. Non-verbal communication problems

(at least one of the following)

- (a) limited use of gestures*
- (b) clumsy/gauche body language*
- (c) limited facial expression*
- (d) inappropriate expression*
- (e) peculiar, stiff gaze*

6. *Motor clumsiness*: poor performance on neurodevelopmental examination
(Attwood 2007, p37)

APPENDIX 3 DSM-IV-R Diagnostic Criteria

For a diagnosis of Asperger's Syndrome, the following criteria must be met:

1. Student must have impairment in social interaction, as manifested by at least two of the following (possible examples with each):
 - **Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction**
 - *He makes limited eye contact with the person in which he is speaking.*
 - *Her facial expressions do not change to demonstrate points.*
 - **Failure to develop peer relationships appropriate to developmental level**
 - *Friends are much younger than his actual age.*
 - *Does not have a large group of peer friends.*
 - **A lack of spontaneous seeking to share enjoyment, interest or achievements with other people**
 - *Does not point out objects that would be of interest to other people.*
 - *She does not congratulate the winner of a game.*
 - **Lack of social or emotional reciprocity**
 - *He interrupts others talking in a social setting.*
 - *She does not understand how to appropriately engage in small talk.*
2. Student must have restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
 - **Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus**
 - *Student talks continuously about a topic of interest, such as Pokemon. He may be able to tell you specific details about every character.*
 - *Parents learn more about World War II battles than they ever cared to know from their daughter.*
 - **Apparently inflexible adherence to specific, nonfunctional routines or rituals**
 - *Student refuses to go to an assembly at school because it is not part of a normal day.*
 - *School began on a two hour delay and she will not do math at 10:30 because math is done at 8:45 .*
 - **Stereotyped and repetitive motor mannerisms**
 - *Student often engages in hand or finger flapping when frustrated or excited.*
 - *Student rocks in seat during times of frustration.*
 - **Persistent preoccupation with parts of objects**
 - *Student plays with parts of toys instead of how the toy was intended.*
 - *Student would rather take things apart than use the whole object.*
3. The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.
4. There is no clinically significant general delay in language (*researchers are debating this topic presently.*)
5. There is no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.
6. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

APPENDIX 4 Introductory Letter and Consent

An Invitation to participate in some positive research on Aspergers Syndrome/ASD.

As part of a Queens University Masters in Autistic Spectrum Disorders, I am conducting some research which will I hope begin to

- Reveal the Positive attributes of Aspergers/ASD .
- Enable young people and their parents to uncover and recognize the important positive gifts that ASD brings to the family
- Create an opportunity to explore the challenge of focusing on the positive and enjoy the experience of doing so.

I would like you and your parent or guardian to be involved.

I am also a parent of a teenager with Asperger syndrome and am especially keen to make this whole research process an enjoyable and worthwhile experience for everyone.

None of your personal details will be revealed at any time, as names will be changed, and you can withdraw your consent if at any stage you are uncomfortable.

If you are interested please provide your contact details as follows

Name.....Signature.....

I would like to be included in this research project and have consulted with my parent/guardian who also agrees

Parent/Guardian Name.....signature.....

Telephone.....

APPENDIX 4 Research Participant Details

Name:

Age

Brothers/Sisters& their ages:

Current School and school year:

Schools history

For what Years

Diagnosis:

Age Diagnosed

Statement Provision: Please state What Support?What Class Assistance?
Additional supports e.g. O/T Speech and Language;Laptops;Software aids.

Describe his friendships:

Favourite Subjects/Least favourite?

Involvement in clubs;sports etc:

Special Interests Over the Years:

What does he want to be as an adult?

What do you think he would be best at?

APPENDIX 5 Interview Guiding Questions

The following questions guide the research interviews, in a semi-structured way.

All the questions are asked in the context of Home School and Community

Young Persons Questions

What is the best thing that has ever happened to you?

What are you Good at or best at? Tell me 5 things!

What are your special interests? Has that changed much?

Why do you think that is so?

How would you describe yourself as a person?

(e.g. Funny,Odd, Intelligent; happy, Original,)

And how would you like others (your family, your friends your school?)to describe you?

What do you like about yourself?

What would you like the world to know about you?

How many do?

What does having ASD mean to you?

(Follow through on key words in answers)

People describe ASD as a disability? What do you think of that?

It's also said that people with ASD bring some real talents, gifts, positives to their families, schools and community.

What do you think? What are yours?

What special qualities do you bring to your family? To your class?

Who supports you and how?

What people or things make it difficult for you to be 'Positive' about yourself and your ASD?

What would make it all a bit easier?

Who?

How?

How would you like to change other peoples thinking?

School Home Clubs Friends?

What are your hopes for the future, work or university or??

Parents Questions

What do you value most about your young person and their part in the family?

What attributes would you like the world to know about him?

How does positive/negative or attributes/deficits balance get lived out in your home? What gets more attention?

What makes it hard to actively celebrate the positive in your son's life?

What support do you/he get in demonstrating' or 'showcasing' his talents?

What could others do to support you/him?

How does school work with his talents, special interests?

How does school get in the way?

What are your hopes for his future?

APPENDIX 6 SUMMARY STATEMENTS

**Peter born 1994. Diagnosed 'moderate Learning Difficulties 2001 aged 6.
ASD diagnosis late 2009'**

Special Educational Needs

First referred to Education Psychology at preschool with concerns about speech and language development and behavioural difficulties at home. Statement recommended placement at special needs school but placement had begun in mainstream primary and all agreed he should stay there. Statement revoked in P2, though social anxiety issues identified and visual memory strength noted. Annual psychologist review until P6. Counselling briefly for self esteem in P5.

First Secondary School (first to third year)- Retrospective report by Education Psychologist included -'Unhappy placement'. 'Socially isolated presenting with atypical obsessive behaviour at home. 'Understand he was severely bullied and school attendance an issue'. Note: No assessment or specialist input was made during the 3 years at secondary school where Peter experienced most distress.

Current Secondary school (since 4th year 2008/9, finishing end 5th year).-Early identification by SENCO of social organizational and learning difficulties in school and concern about mental health at home so referred to education psychology. Medical referral made and school addressed all else through an IEP. Re referred June 2009 due to concerns about learning, and seeking additional school support. by which time ASD diagnosis already made through CAMHS.

Current provision - AN IEP with 'targets relating to his social and emotional well being and ability to follow instructions and understand what is expected of him.'

'Strategies provided- Chill out room to use at break and lunchtimes'.

Assessment

‘Pleasant and courteous and well behaved.’ Inconsistent profile of strong non-verbal skills compared to weak verbal skills and very weak working memory and processing speed skills. Overall score within range for moderate learning difficulties, though variable profile may mean unreliable evaluation of ability. Below 2nd centile on Maths ability. Literacy attainments ‘quite good’ given his level of ability. ‘Clearly hampered by inability to make inferences and draw conclusions.’

No Statement written due to leaving school that year.

Teacher/School Input

Only 4 teachers responded to information request. ‘Given that ‘most of those who responded did not indicate that he was very demanding of their time, in my view he does not require additional adult support.’

General guidance recommended for school provision – IEP targets focussing on understanding of instructions, organization, emotional well being and maths development. Consider allowing school-home email for important school notes or homework. Social stories to help him understand situations where he perceives he is being bullied or made fun of.

Peter’s Views during Education psychology assessment mid 2009-

Scale of 0-10 he rated school a ½ in terms of happiness. The half reflected ‘supportive teachers.’

What would make things better for him-

If everyone in his class stopped laughing at him and treating him like the court jester.

Certain individuals kept out of his way and didn’t speak to him.

Teachers chunked his work and gave him short breaks.

Teachers explained instructions more clearly

He was better organized and brought books to class.

'He is keen to study electrical construction work at tech. after school.'

Post Diagnostic Recommendations

Name forwarded to Clinical Psych Team re Parent workshops.

Information on any local and regional support groups. (none existing).

APPENDIX 6 Summary Statements

Michael born 1996. Diagnosed 2005 with ‘ASD, ADHD, Speech and Language and dyspraxic type difficulties. Formally Developmental Coordination Difficulties’

Special Educational Needs

Difficulties consistent with ASD and ADHD in areas of concentration, social interaction skills and self organization. Benefits from structure and routine in classroom and quickly frustrated when task is challenging or when things do not go his way.

Assessment

Average/low academic ability capable of mainstream.

Michael is ‘considerate and well mannered.’

‘Needs to be made aware of what is appropriate and reminded how to conduct himself with others.’

‘Genuinely affectionate, well humoured, very popular with peers.’

‘Demonstrates empathy and remorse and quick to apologise when he is aware that his behaviour has been inappropriate.’

Statement issued P7

Acquire skills in reading and written English.

Further develop oral communication – expressive and comprehension.

Improve interest and skills in social interaction.

Social and behaviour adjustment enabling conformity with classroom routines.

Develop concentration and attention to develop more independent work habit.

Recommending

Continued access to an appropriate level of adult assistance, to support staff. in areas of social and behavioural development.

Supervision in unstructured settings.

Promoting appropriate classroom behaviours.

Clarifying verbal instruction. Supporting work programmes. Assisting personal organization.

Promoting positive social interaction with peers.

IEP addressing Michaels individual needs graded to suit his pace of learning.

Access to a structured programme of integration into new school setting with designated member of staff taking responsibility. etc.

These recommendations are not spelt out.

APPENDIX 6 Summary Statements

Craig Born 1994. Diagnosed 'ASD Asperger Syndrome 2007(second Year) during inpatient stay at Child and Family Unit.'

Beginning of second year - Became 'angry, distressed frustrated and threatened self harm.'

'Also complained of Bullying by peers and older pupils which when investigated appeared to have little or no foundation.'

Admitted following a 'severe mental health breakdown.'

Special Educational Needs -

Social Emotional And Behavioural Difficulties from Asperger Syndrome and mental health difficulties.

High Level of Anxiety, rigidity of thinking and resistance to change.

Relationships with peers. Difficulties with concentration.

Assessment

'Superior Intellectual Ability'. At risk to himself and others increased by pressure readjusting to school life.

Extremely pleasant and polite. Mature social and language.

Parents report him very affectionate and attached to his mum'

Statement recommending

A curriculum suited to the needs of above average intellectual ability.

Unquantified Adult Support.(Full time class assistant provided).

AN IEP to

Help C to form friendships with other pupils through involvement in activities in areas of shared interests.

Being aware of sources of anxiety for him and early signs of social distress.

Offering C the opportunity to discuss at any stage through school pastoral care system ongoing difficulties that may arise.

To be coordinated with ongoing support that may be provided from Child and Family Services.

Help C develop positive and adaptive strategies to cope with difficulties – real or perceived – in school.

Helping C to develop insights into his behaviour and that of others which defuse the sense of anxiety or threat which he may otherwise perceive.

Help him recover concentration and motivation for school-related tasks.-

Ensure anxiety levels about work and social relationships are identified and defused at an early stage.

Develop strategies with him to plan his workload. Suggests some form of visual schedule. This would allow him to tick off work he has finished and reinforce his sense of achievement. Strategies such as these should help to reduce his anxiety about school work.

No input from Craig in these reports.

APPENDIX 6 Summary Statements

**David Born 1995. Diagnosed 'Asperger Syndrome aged 7 years 9 months.
Diagnosed ADD aged 13'**

Moved from first grammar school after first year. Moved to another Grammar school after second year recovering in small new integrated school. Statement reviewed aged 13. Parents helped shape the statement recommendations.

Difficulties First Year-

Concentration, ability to follow group instructions, organization skills, difficulties with homework and communicating with peers.

Second Year (Second school) High level of one to one support mainly developing social and communications skills and touch typing skills.

Improved relating to peers and managing own needs.

Improvement describing feelings and self esteem and awareness have gradually improved. Communication skills one to one greatly improved.

Assessment aged 11. Peaky profile 96th centile verbal ability. Non verbal 3rd centile presenting a very 'peaky' profile of skills. Verbal score judged better predictor of academic achievement. Suited to Grammar School. Judged 'cognitively astute.'

Invisible 'stimming habit' idiosyncratic teeth touching slowing reading and writing skills.

Co-operative in class. Responds well to structured lessons. Teachers report makes valuable thought provoking comments. Sometimes inappropriate. Maths skill. Sets himself very high standards so precision and care influenced IQ test scores.

Occupational Therapy report aged 13 noted significant vestibular, auditory and multisensory sensory processing difficulties. They noted precise effort with fine motor tasks which slowed down task completion and lowered scores. Long list of

recommendations made and written guidance provided to parents.. No further provision made.

Statement Recommending (wording shaped by parents)- full time classroom assistant to assist-

Emotional Well Being – Develop understanding of learning process and have more realistic expectations of himself. To reduce anxiety.

Nurture self esteem through positive predictable learning environment.

Communicate clear unambiguous expectations and positive feedback and praise when he models correct approach.

Learning Style – to follow class routine, participate in class discussions and work effectively alongside peers. Improve ability to work independently.

Social and communication Skills-Improve ability to interact with others, extend social network using befriending strategies, Improve understanding of everyday language. Communicate own needs effectively. Develop self organization Skills.

Use strategies help cope with emotional and social demands of school. Use a versatile, flexible style of teaching. Named liaison teacher for home school communications.

Self Assessment David self assessed at end of 2nd year on Strengths difficulties Problems and Out of School Interests and copy inserted into statement review.

APPENDIX 6 Summary Statements

Keith Born 1998. Diagnosed 'ASD privately 2008 age 10' - not accepted by Education board and tribunal in process. Diagnosed ADHD 2004.

Assessment

Mental Health Interview following parental referral due to 'flattened mood, repressed appetite and Keith's letter to mother. Family history of ASD and father's mental health history.

Assessed as -Pleasant young boy showing tendency to think literally. Difficulty distinguishing differences in facial emotions and expressions.

'No evidence at interview to suggest any significant mental health difficulties or depressive disorder.' Practitioner agreed to write to Education Psychology due to him presenting with 'literal thinking, difficulties understanding social situations, causing him frustration and stress in the classroom.' School attendance deteriorated. Responded well to earlier art therapy through CAMHS aged 9.

Occupational Therapy devised home and school treatment programme May 2010.

Recommended –'one-to-one support in order to help him complete homework and class-based activities' To address Postural stability; Bilateral integration and sensory processing.

School referral to Education psychology 2005 Assessed 2007 aged 9

Switching off during class discussion. Special interest in history and detailed knowledge in special interest area Homework attitude deteriorating.

Less well liked by peers because of his behaviour.

Responding inappropriately while being told off. Standard of work a little below class level, except science. Assessed cognitive level average ability.

Diagnostic Assessment (private)

The report refers to Health Trust assessment based on observation of a group assessment with nine children over six weeks, but without full developmental history or standardised diagnostic schedule e.g. DISCO(Diagnostic Interview for Social and Communications Disorders

Endearing child who cooperated well and was motivated to complete set tasks. Cognitive Function tests reveal thinking and reasoning skills above average. Literacy and numeracy are average but much lower than expected in mechanical mathematics and would benefit from individualised programme to deal with this.

No significant difference noted between verbal and non verbal skills.

Recommends that 'Keith's curriculum is well differentiated to reflect his profile.'

Presents with a pattern of behaviour that stems from a central problem of social communication and symbolic development which affect how he processes information and makes sense of the world. Propensity towards repetitive activities and routines.

Suggests a direct link between his ADHD and sensory processing difficulties which has implications for how he learns and how his teaching and learning should be organized.

APPENDIX 7 David's Poem

Untitled

This ain't for the hundred in cash,
Ain't so I can see this in a book,
It's just so I can say I made you look,
Cos I ain't your everyday cheesy poet
And ya know it,
I'm in this cos I cant live if I don't spit,
I've always been raw from the start,
Always stay raw at heart,
Even when the world is falling apart.
So before you miss my point
Listen closely to what I'm saying in this joint.
I toss coins to the kids shaking cups on the pavement,
As they be beggin' for payment
And I'm begging for listeneners.
Cops wanna lock me up,
Cos they beggin for prisoners.
See, since the moment of birth
I've been the most hated on Earth
And it's gonna be that way till I'm under the dirt,
Cos there's something about me that you all despise,
Something scares you away when you look in these eyes
And I never knew what it was,
Guess I never will,
It's a disease that can't be cured by a pill.
So you can tell Jesus,
I would have stayed awake in Gethsemane,
I keep my eyes open till I've destroyed
The last of my enemies.