CONTRADICTION IN TERMS

How an Oppugning Schooling Placement and Environment can Adversely Affect a Child's Mental Health & Emotional Development across the SEND Spectrum.

"An ounce of prevention is worth a pound of cure.
It's more prudent to head off a disaster beforehand than
to deal with it after it occurs."
– 'De Legibus' (c. 1240)

"Meet the malady on its way." ~ Persius (A.D.c 58)

J. H. Willicott

Independent, Theoretical and Empirical Reference Guide for all SEND Spectrum Children as used for Bastian Willicott in support of case reference: [BWillicott vs UK 17275/15 – 39415/16] at the European Court of Human Rights as underpinned by the United Nations

Dedicated to:

Moose, my Agapimou ~ Love knows no bounds, Never Give Up

&

To Thousands of Voiceless Children, Be Brave and Be Heard

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&

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“In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”

– United Nations Convention on the Rights of the Child, 1989 (Article 3)

“The child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity.”

– Convention on the Rights of the Child, 1989

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CONTRADICTION IN TERMS

How an Oppugning Schooling Placement and Environment can Adversely Affect a Child’s Mental Health & Emotional Development across the SEND Spectrum.

Overview of Comparable Theoretical Literature and Empirical Evidence in support of and in recommending that, Bastian Willicott is educated according to his need and that his voice is heard, by exercising his right, through National and International Legislation.

Normal-Like-Me, Specialist SEN Research Services Limited – 10176663

INTRODUCTION

“Each of us, as citizens, have a role to play in creating a better world for our children”
- Nelson Rolihlahla Mandela

"Preuention is so much better than healing beause it saues the labor of being sicke," Thomas Adams's "Works" 1630

Bastian Willicott, a 12-year-old male, who is one of six persons worldwide diagnosed with SETD$_5$, a complex Genetic, Neurological, Intellectual disability ascribed to (De novo loss Micro Deletion) - in addition to SETD$_5$ a damaged Corpus Callosum.

As Bastian is constantly referred to as an enigma, trying to obtain any relevant data and or analysis other than the research undertaken by Cambridge University and subsequently published in the American Journal of Genetics, describing him and or his needs or trying to reference them was all ways going to be difficult but as his principle researcher, observer and analyst over the last 12 years, I have gained expert knowledge in trying to match theory, and empirical evidence to SETD$_5$ and his complex needs.

Applying scientific / medical data to reports for any educational court case involving rare disabilities would always yield difficulties, so setting up a specialist SEN Research Company, was always going to be way forward. Case/disease/syndrome specific in-depth research analyses for rare and variant rare neurological conditions would have to be a plethora of published data, environment placement data and hands on parental experience so as to evidence the specific need of each child.

This research report in both a mixture of parental and professional analysis and is to be used to evidence Bastian Willicott’s needs as well as acting as guidance for parents of children trying to access specialist provision based on their individual needs within educational institutions as well as guidance for both Educational Institutions and Educational and Social Care Government Departments.

It is often extremely difficult in coming to terms with being born different/‘indifferent’ however it is even more difficult when one has ‘Double Exceptionality’ intelligent yet equally intellectually disabled at the same time. This often results in one being marginalised and placed *outside of the usual tick box measurement scales*; causing a detrimental effect to one’s perception and psychoanalytical behaviour. Force matching legislation to human capabilities regardless of ability especially in rare conditions with little or no measurable scientific data will always have an adverse effect on a child’s development, affecting in particular, their mental and emotional wellbeing especially when placed in an environment that is not conducive to their own personal belief and thinking.

As principal researcher and parent I have tried to collate a series of empirical and theoretical approaches that can best describe the damaging effects a child can and does and could sustain whilst being placed in an environment not conduce to their own self-appraisal and awareness.

INDIVIDUAL DIFFERENCES
Guidelines for Education Practice
Bassett, G.W

1978

School Organisation

Clearly, it is, the whole learning environment that determines the curriculum as it is experiences by children and all the factors that help to create this environment. (Individual Difference)

If the problem of catering for the needs of individual pupils is to be taken seriously school will have to grapple with the task of attesting to create their own curricular, rather than simply dispensing those that are already prepared.

Since the curriculum is the heart of the school experience for children, it is obvious that the organisation of the school / LA should endeavour to create the best conditions for its objectives to be realised. In fact, the organisation is not always responsive to the spirit of learning, sometimes hindering rather than helping it or being in various ways less supportive than it might be. Often an organisation of a school has been determined by past policies, however with the continuum of educations, and being taught in the present it can be seen to be dysfunctional and or indeed harmful to the child.

Neagley & Evens: The environment / curriculum is about discipline; however discipline and individuality are not incompatible, on the contrary, discipline is one of the most mature expressions. For teachers and others who need to create disciplined situations in which the children develop and strengthen the child's capacity of self–discipline, by practicing the exercise of responsibility, an understanding of his needs interests and limitations are essential and therefore also seen as an insight into the kind of learning environment that he is stimulated by and therefore accommodations can transcribe about individual differences amongst children.

Modern education is defective; because of failure to create conditions of learning which strengthen self-discipline expressed as interest, effort, initiative, a striving for high standards of achievements, sensitivity to human feeling and concern for others.

Heterogeneous Grouping

However homogeneous grouping is done and however sensitivity readjustments are made as changes occur in students, by the very nature of process, the individual cannot be at the centre of interest, i.e. interests, aptitudes or by relating these to those of other children and as qualities of the abstract 'child' but the person as a complex entity eludes us.

Thus, not surprisingly the search for forms of organisation that do cater better for individual children leads to greater acceptance of heterogeneity in grouping. This is therefore regarded by some as an acceptable condition for individualisation of teaching by other as a positive advantage. Schools that favour heterogeneity tend to make capital out of individuals differences by encouraging productive interaction between members of the group.

The atmosphere of happiness, confidence and serenity which characteristically pervades classrooms was found in the Collett School in Hemel Hempstead, Hertfordshire. The Collett School provides this exact environment whereby children with ‘double exceptionality’ are accepted based on their own individual perceptions.

Affective Component of Discipline

The capacity of individual children for intrinsic interest in various tasks differs greatly according to the variety of experiences in the home and community, and according to their perception of the relevance of these tasks to themselves. In particular the reaction of children to the contrived environment of the school in which specific values may be stressed will differ also according to their common ground with values known to them and accepted by them.

Mature intellectual values such as the importance of objective inquiry, social values such as toleration of difference, fairness, truthfulness, responsibility, compassion, and aesthetic values which underlie the arts, all of which are of special importance in the civilising work of a school / will be reacted to very differently by children according to their familiarity with them, and reinforcement of rejection of them in and out of school experiences.

Home and Community Influences

We must look at specific motives, values attitudes, expectation and self-concepts as learned characteristics and seek to understand individual differences in the light of each child idiosyncratic experiences. The planned experiences provided by the school to assist the pupils in attaining the designated learning outcomes to their best abilities, ***but*** there may also be a hidden curriculum not planed and not explicitly recognised, consisting of children’s experiences at school that arise from organisational features, ‘attitudes, expressed or implied by teachers or situations’ as an attitude expressed by the children that exist although not part of the official programme of the school, such like – ‘contacts with other children that occur informally, whereby these being either being ***beneficial or harmful***’ thus altering the progress of the child made thus far, i.e. learnt behaviours. These learnt behaviours are brought on or created by in part by the child himself, or in part by his past / previous social-psychosocial environment and in part by his perceptions and interpretation of self and that of his social environment.

There is a need for additional financial assistance to schools where the need for individual alternation is more pressing.

Home and School

If influence at home and school are antagonistic, the child is caught between these contrary influences and most adversely affected. A child would then attempt to live a divided existence, causing strain and affecting his life both at home and at school. Since both school and home are powerful influences on cognitive and social development. Home and school have different origins and circumstances, as well as having different values, expectations and goals.

The child's personality is an important element. Personality is complex. The neurological development and genetic coding as detailed by the $SETD_5$ Genetic sequences highlights this by relaying the importance of the chemical Dopamine, and how the receptors D_1 through to D_5 alternate the reward system. Dopamine is the ultimate reward system and feeds on both negative/positive reactions thus resulting in either, following a complex negative reward learnt behaviour or the positive rewarded learnt behaviour processing. That is why shifting a child or adult with the negative dopamine reward is far harder to psychologically progress than were the child/adult to have been following their positive dopamine reward receptor based on the environment best suited to the individual.

Personality/disposition is a complex product, varying in infinitely subtle ways from person to person; broadly influenced by social class, peer group, race, religion, home and school, but each is therefore complexed and interrelated. Therefore, it is the home that has the most influence as seen by the child's motivational pattern. i.e. 'striving for achievement, capacity for independent action will affect his/her attitude, aspirations and expectations together with self-concept all of which have a direct carry over into the school learning environment'.

The child's sense of discipline is accepted as indifferent at school. This acceptance of school, his involvement and social relationships 'with teachers and other students, his capacity for concentrated and independent effort, his sense of discipline and confidence as well as striving for achievement are largely determined in the home as by contrast are his rejections of school, ***social maladjustment***, his insecurity and over-reliance on social approval and or lack of ambition.

Linguistic Development - Cognitive and Linguistic Functioning

Environment plays interrelatedness in all aspects of a child's development which equate to the changes of the child. The emphasised dangers that may arise when we consider in isolation one characteristic or group of characteristics of a child are the cognitive and linguistic styles and abilities.

These cognitive and linguistic styles and abilities are but a few of his overall characteristics and influenced both their development and vitalisation by his view of himself and his perceived place in the world and his confidence in the future. Knowing a child's intellectual abilities is a first step, but needs constant refining to the preferred cognitive style and psycholinguistic and socio-linguistic competence but a child's response is determined by particular characteristics – affective, cognitive and psychomotor – that defines his/her uniqueness.

Environment determines the variable in Cognitive and Linguistic functioning

Variation in environment could be associated with variation in intelligence,

1. Genetic influence
2. Environmental influence

Thus, at individual level at functioning his/her effective intelligence is determined by complex interactions between learning and environment.

A child who receives a favourable genetic endorsement will, if raised in stimulating circumstances reach his/her potential, theoretically at least to the full. However, the same child may well encounter environments adverse to his/her development, if so, he will be functionally duller than might have been.

Environment stimulation must be appropriate to his/her level will enable him/her to realise that potential, inappropriate environments will ensure that he/she realises or actualises only ***some*** degree of that already limited potential.

Many children are advantaged by receiving an environment catered to their individual needs or by hereditary, whereas other children are doubly disadvantaged were they to be placed in an unsuitable environment not suited to their individual needs or by a displaced hereditary.

The grand matrix encompassing the results of all prior interactions between heredity and the environment consist of selective predispositions both to undergo change and respond to environment in particular ways.

Shelly Shah states: "The essential characteristics inherited by all human beings are physical structure, reflexes, innate drives, intelligence, and temperament. There are some biologists who claim that the difference in the traits or qualities of individuals or groups are due to the difference in their heredity. They are duly supported by some psychologists and sociologists in their assertion, that like begets like.

Man's behaviour is influenced by two forces: heredity and environment. The biological or psychological characteristics which are transmitted by the parents to their off-springs are known by the name of heredity. Heredity is, in other words, a biological process of transmission of certain traits of behaviour of the parents to their children, by means of the fertilized egg. Heredity traits are innate; they are present at birth.”

Interaction of Heredity and Environment

All traits depend both on genetic and environmental factors. Heredity and environment interact to produce their effects. This means that the way genes act depends on the environment in which they act. In the same way, the effects of environment depend on the genes with which they work. (Indiana Education)

Children must be emotionally free to learn (free from disruption/distraction as this has a direct impact and is related to how learning is affected or altered in an environment by means of incorrect and unsuitable placement at special educational schools/institutions).

Understanding Individual Differences

There are inherent problems in monitoring human behaviour therefore a significant difficulty about the nature of the units and scales used when measuring as stated; therefore identifying behaviour can be broad and in the dimensions significant. A huge variable based on the norm is used.

A rare and unique child does not have a normal scale, therefore there is a doubt regarding the validity of tests in relations to their behaviour and or intelligence especially their self-belief and perception of themselves in greater society.

A child’s performance in a ‘test’ is a part of the pattern of a behaviour which is peculiar only to him. The more complex the behaviour in question the more it is likely to mirror personal expense and environment. Therefore, the measured test is not the same as another.

A major question for the educationist is the degree to which difference is inborn or learned and its implications for the complex interactional pattern of congenital and environmental influences in behaviour. If behaviour is fixed by congenial factors, it can be limited in the education environment but if the environment is modified or different the education is more influential.

PROXIMAL ‘ENVIRONMENTAL’ VARIABLES AS SOURCE OF VARIANCE

Parent Child Relations

Early environment equals intellectual growth. The importance of an environment rich in sensory stimulation is evident when one considers Piaget’s Theory of first basic development.

SENSORY – MOTOR – INTELLIGENCE

1. Intellectual Relationships
2. Affective Relationships
3. Interactive Patterns

Analysis of Environment

1. Categorical grouping
2. Relational – contextual grouping
3. Analytic or descriptive groupings

    - Association with longer attention span, greater reflecting, greater emotional control and more marked social independence.

Cognitive Style

Cognitive style subsumes a variety of cognitive behaviours; perceiving, organising and labelling.

‘Sigel’ argues, “individuals have preference to particular modes of categorisation, possessing distinctive properties therefore not just fact of individual difference but self-consistence, i.e., one individual surrounded by a host of stimuli, to which he will attend in addition to this his style determines specifically his utilisation of his intellectual abilities.

There are different learning styles/components:

Sensory orientation, responsive mode and thinking pattern, i.e. some pupils prefer a preferred education: sensory style;

1. Visual clues from environment
2. Touch
3. Eyes ‘Brunner /Nations postulations’

Medically and neurologically Bastian falls into the 0.000001% of the global population being the rarest, diagnosed as one of six in 7 billion therefore creating realistic statics / tick boxes for education purposes are of little value and only highlight the total and utter lack of any individual appreciation based on the complexity of his particular needs.

Bastian would fall into the 2.4% of the population known as ‘mildly intellectually handicapped based on ability; but because of adopted approach from education environments it ranges from 70-79 (5.6%) / to 80-89 (49%) but in his syndrome it is more likely to be 20-49 being 0.2% more severely intellectually handicapped. This would be an approximate because testing must always allow for errors and or measurement not being an adequate measure for rare children.

Moreover, as described and coined by (Diane Montgomery), the extremely rare fall into a further category, a ‘contradiction in terms’ – ‘Double Exceptionality’. This is again highlighted by the environment in which a person / child thrives; when the environment is suited to the individual, despite his/her ability or handicap, the environmental setting can either adversely hinder or positively influence their own progress as their perception to is directly related to the reward, again as influenced by their own dopamine receptors. As in the case of Bastian, his ‘D_5’, is positively activated by an environment which he perceives as safe; leading to an overall positive learning experience and thus firing of new neurological pathways.

Growth in Cognitive Abilities

1. Cognitive development equates to quantitative grown i.e. growing older therefore more ability.
2. Generalised growth equates to older adolescent growth stats.
3. Therefore, Ausubel and Sullivan comment: “Bright / dull and unique children grow intellectually at different rates with respect to environment and cognitive ability and the greatest change is where the child is in constant interaction with is environment.”

Emotional and Cognitive Development

In order for each child to successfully negate each stage it is necessary that he/she be:

1. Genetically ‘normal’ and psychically intact
2. Reach adoptive stages from his environment
3. Satisfactorily resolve problems

Therefore, as a child with a genetic interference and complex rarity, it is best to place such a child in an environment that will aid these milestones, where the child feels in control to learn naturally from an environment conductive to his needs and stance.

The interrelation between emotional disorder and learning disability require the consideration of a number of development and mental related issues.

1. Potential, comprehension and performance
2. Emotional and cognitive development
3. Cause of psychological disorder
4. Factors required for scholastic achievement
5. Patterns of behaviour
6. Primary emotional disorder and learning disability
7. Management
8. The future

In view of the above, we are brought to the conclusion that we must look at specific motives, values and attitudes, expectation and self-concepts as learned characterises and to seek to understand individual difference in the light of each child’s idiosyncratic experience, created part by himself and the interpretations of his environment and in part by his perceptions and interpretations of a socialising environment.

The traditional principle of homogenous grouping: i.e.; special schooling, can be seen as critical as per pupil variability. Homogeneity among a group cannot be achieved if all respects because of the UNIQUE pattern of traits, aptitudes and interest of each pupil. A group that is homogenous in one respect is likely to be heterogeneous in others. Hence only a partial solution is attained. Not all individual differences are equally significant, and that heterogeneity among other important characterises need not detract from the value of homogeneity based on more important ones such as intelligence, special aptitude or vocational ambition.

There are however genetic factors that set limits to achievement, and there are qualities that make behaviour consistent and or predictable BUT it is also true that most forms of behaviours can be mortified by environmental changes.

What are assumed to be fixed moods of behaviour and predictable levels of performances are usually uncritically examined products of particular environments and beliefs and these may change as the environments and beliefs change. Fixed homogeneous groupings tend to reflect the reset circumstances than future possibilities.

All Learning is Individual

Schools as a social institution - in its effectiveness/ineffectiveness most depend to a substantial degree, on the kind of climate it creates. A school like a good family, creates an environment that both stimulates and protects, it encourages children to attempt new tasks and to experiment with human relations without the threat of punitive measures in the event of failure. ***If the school is perceived by children as relevant and satisfying in this way, it is to be this extent likely to be efficient***.

When a school creates a fear of failure and a threating / indifferent atmosphere and its curriculum and or environment is not aligned with the needs and interests of children, it fails to interest them, and must be deemed inefficient no matter what other favouring conditions exist, such as qualified teachers, modern buildings or other interested parents/parties.

School and or classes are likely to take different forms of character although guided by the general objectives and or the same general understanding of children. Each school interprets its particular character by the community in which it is set, nature of children and special interests and skills. This understanding is likely to increase the prospect of the efficiency of and in the school.

[“Just as a school can perceive and interpret its own environmental framework; so should a child be allowed to perceive and interpret his or her own individual notions when it comes to learning” – Willicott, J (2016).]

Most areas of inequality in social settings are entrenched. USA – Supreme Court 1954 – Doctrine of ‘Separate but Equal’ was rejected, Segregation in itself was pronounced to be a form of inequality and therefore illegal.

SPECIAL EDUCATION NEEDS INCLUSION AND DIVERSITY
Norah Frederickson, Tony Cline

2009

1. The child's perspective – Learning the voice of the child.

    - United Nations Charter: Rights of a Child – Article 12

    In securing a special educational school based on Bastian's individual needs, and perceptions as well as including his voice being heard, an 18 month research period ensued from 2012 to 2014 which covered an area of 19096km². Taking in its entirety the South East of England, which included the whole of London (1562 km²) and neighbouring South Middle East counties, as far afield as the entire Hertfordshire County (1642 km²). The research was undertaken by the Parent of Bastian and followed up by a qualified Community school nurse known to Bastian for 6 years, Primary Education SENCO known to Bastian for 8 years, and a CAHMS Head of Department across three NHS Trusts – Analytical Psychoanalyst known to Bastian for 5 years.

    Childs Choice:

    1. School Environment
    2. Special Needs
    3. Friends
    4. Out of School extra curricula and social interactions
    5. Feelings and Emotional wellbeing
    6. Future

The Department of SEN Local Authority London Borough of Barnet has known of Bastian and his complex needs since the inception of his STATEMENT of Education in 2006, with the Head Educational Psychologist stating – "It is unlikely that Bastian will ever get a suitable placement for his individual needs as the Special Education team will never allow it, you may as well stop researching placements as a concerned parent to your enigma child".

Bastian’s communication was sadly not upheld and wasn’t allowed his voice and indeed his rights, he wasn’t even asked.

‘Parental involvement was dismissed’ – which should have included

1. Democracy
2. Accountability
3. Parental Choice
4. Engaging Standards
5. Tackling disadvantages and improving equality
6. Addressing social problems
7. Resources
8. Advocacy
9. Human rights
10. Emotional and wellbeing based on rare and complex dual children

SEN (Special Educational Needs): Individual deviations from normal expectations on significant difficulties in learning compared to the majority. There are two conceptualisations of nature, of these difficulties, which are often compared and contrasted; SEN is best understood by looking at the individual differences and an alternative approach which argues that SEN arise when inappropriate environmental demands are placed on an individual which exceed their current capabilities for meeting their demands.

Environmental Demands

Children’s current attainments reflect the nature and quality of previous learning experiences and that children will learn when in an appropriate environment, conducive to their own perceptions. Environmental demands leads to an analysis of disabling environments and hostile social attitudes rather than individuals and their different function and abilities.

Interactional Analysis of SEN

An interactional analysis view the level of need as the result of a complex interaction between the child’s strengths and weaknesses and the level of support available and the appropriateness of educational environmental practices.

Parity in Partnerships

A partnership between parents and professionals implies mutuality of respect, complementary expectations and a willingness to learn from each other. Parents are experts on their child and can influence attitudes and attainment needs be recognised respected and acted upon. In best partnership practice, the process of decision making is most effective when professionals acknowledge and incorporate this parental perspective and seek constructive ways of reconciling different viewpoints.

Diversity

While some parents have common issues, they do not all have the same/similar needs. There is diversity not just in culture and interests but also in resources. Proper accounts should be taken of such differences to ensure all parents can be supported to meet their children's SEN.

SEN and education provision

SEN are taken to be the outcome of an interaction between the individual characteristic of learners and educational environments in which they are learning. This means that if we are to fully understand learning difficulties experiences by some children, we have to consider the curriculum and learning environment being provided by them.

The importance of this sort of intergraded approach is widely recognised and advocated.

The SEN COP (Code of Practice) equates to the following:

The assessment should be four-fold –

1. Child's learning characterises
2. Learning Environment that the school is providing
3. Tasks
4. Teaching style

Goocher et.al state: "In the United Kingdom, it appears that in practice, it's more often reflected as a 'with-in child' model of SEN, based on the deficits within the child and very little attention was given to the learning *environment*. (1998)

Frederickson and Cline, state: SEN identification therefore needs intervention into an analysis of educational curricular and learning environments. (1995)

SEN Code of Practice (Department of Education & Skills 2001) – Learning environments, learning tasks and teaching styles should all be assessed together with learning characteristics of individual children.

However, SEN assessments focus on the '***within-child***' factors and not on the individual child by holistic individual characteristics - Mckee and Witt, (1990), suggest this, because professional Local Authorities lack real knowledge and confidence in other forms of assessments.

Emotional Intelligence

The ‘Emotional intelligence’ role is affected especially around emotion and is often always most certainly overlooked in all discussion of social skills (Crick and Didge, 1994).

1. Knowing one’s own emotions
2. Managing emotions
3. Motivating oneself
4. Recognising emotions in others
5. Handling relationships

Peer relationship skills map closely onto handling relationships and self-management skills.

Emotional intelligence involves the ability to perceive accurately, appraise and express emotion, to access and or generate feelings when facilitating thought as well as the ability to understand emotion and emotional knowledge. (Salovey& Sluyter 1997)

CHILDREN'S SOCIAL AND EMOTIONAL WELLBEING IN SCHOOLS
A critical perspective
Watson et al.

2012

Children's wellbeing in schools is revealed as inconsistent inherent in the concept and explored and operationalized in schools and in the role of educational professionals as well as in perpetuating a belief to make children well with agendas or policies.

Wellbeing concepts include:

- Welfare
- Law
- Childhood
- Philosophy
- Politics
- Health
- Psychology
- Anthropology
- Culture

These concepts are all a part of the puzzle but don't fit together. Immanence and possible effects of concepts on embodied children are i.e.

- Rights
- Social Responsibility
- Happiness
- Furthering Capabilities
- Functions and Life Skills
- Participation
- Respect
- Positive engagement
- Education Achievement

Wellbeing needs to be improved as currently it is inconsistent. ECM 'Every Child Matters' (England and Wales) is the current measurement/vehicle for wellbeing. Wellbeing programmes, i.e. Social and Emotional Aspects of Learning (SEAL) and the United Kingdom Resilience Programme (UKRP) offer no sound continued evidence.

This does not support genuine mental health problems and normalises emotional fragility for all children. Care and support are poorly defined and lacking in wellbeing. Wellbeing is deemed seconded to education when achievement agendas are set. Children have choices and a voice as set out in the United Nations Charter (International Law), Child Rights Charters (International, European and National Law) and European Court of Human Rights (Europe) and The Human Rights Act 1998 (United Kingdom).

Challenging Stigmatising Notions of Difference

If the UK based their approach on a relational *Ethics of Care, Wellbeing, Inclusion*, education would become synthesised into positive experiences.
In the deconstructive process – wellbeing becomes a concept and wellbeing disappears, thus subsumed in other concepts rather than being a therapeutic and pathologised agenda layered onto education discourses to compensate for the deficits of the few.

Human Flourishing

Children do not flourish in isolation from other or in indifferent environments they form and maintain relationships provided the platform is correct. Wellbeing is interrelated and inter-rationalised in human encounters.

If individuals are not authorities on what a flourishing life is for themselves, who, if anyone is? No one (government, institution, authority, educational establishment) can lay down in detail how a person will best flourish in the future. There are simply so many ways of thriving, so many forms of wellbeing. Relational Ethics equates to children having a voice.

The need to challenge ‘majoritarian’ perspectives on children’s wellbeing that normalise what wellbeing should be and consequently pathologise and problematize other ways of being well.

One of the purposes of education in a democratic society is to equip people for a flourishing life, thus therefore becoming better informed contributors to national and global conversation. (White, 2007)

The intelligent action demands recognition of three inclusions; relation, action and reflection between experience and knowledge. Therefore, having a ‘within’ and an ‘outside’ education community constantly facing harsh unlawful budget cuts only creates an inherent inequality resulting in discrimination. Discrimination exists and occurs across many of society mechanisms and it is this that creates a disenfranchised child, parent and society.

At no point in the chronology of case proceedings did the UK Government and in particular the London Borough of Barnet ever listen to the voice of Bastian or listen to the parental expertise, nor did they apply the Human Rights Act or even take into consideration The ‘UK Strategy for Rare Diseases – 2010 (In 2009, a recommendation of the Council of the European Union called for each EU State to have in place a rare diseases plan or strategy by the end of 2013 (2009/C 151/02).

RARE DISEASE STRATAGEY

THE RARE DISEASES STRATEGY contains over 50 commitments to ensure people living with a rare disease have access to the best evidence-based care and treatment that health and social services, working with charities, researchers and industry can provide.

The UK commitments are in 5 areas:

1. Making sure patients and their families and carers have the information they need, are listened to and consulted
2. Developing better methods of identifying and preventing rare diseases
3. Improving diagnosis and earlier intervention for those with a rare disease
4. Developing better coordination of care for those with a rare disease, including joined up consultation and treatment schedules
5. Building on research to improve personalised approaches to healthcare for those with a rare disease

- Continue to develop service specifications for rare diseases. This will include country specific care pathways and a ‘generic’ care pathway that sets out best practice that can be applied to all patients with rare diseases in the UK (particularly where there are no disease specific pathways). The generic care pathway will include:
    - Setting an appropriate care plan for all patients with a rare disease clearly stated principles around the standards of care which patients with a rare disease can expect, including patients with no diagnosis.
    - Development of seamless pathways for transition, from childhood to adolescence, and on to adulthood and older age.
    - Access criteria and measures of quality and outcomes.
    - Work together to identify a selection of the rare diseases most suited to the development of best-care pathways and proposes other rare diseases for possible pathway development, taking on board the needs of patients and carers and the challenges faced during delivery of the first set of pathways.

- Strengthen the mechanisms and opportunities for meaningful and sustained patient involvement in rare disease service provision and research, recognising patient groups as key partners – including in the development of the four country plans to implement the Strategy.
- Improve awareness amongst service providers and others of the effects that rare diseases can have on a person's education, family, social relationships and ability to work.
- Encourage effective and timely liaison between the NHS and other public service providers and encourage providers to consider the effects of rare diseases on people's lives when they are developing and managing services.

ECM – Every Child Matters therefore has made it more difficult to perceive children's wellbeing as a broad and interconnected concept.

Ethical Practice Personal Qualities

Past and Present Professionals ARE important, so too are their reports, often the professionals' reports take into account a sustained period of intervention often over 6 years' worth of variant analyses to be used for complex and rare persons. These reports are to be used in line with ethical practices and should not be dismissed due to an apparent budget cut.

Rights

Rights is a contested concept; rights are a matter for moral reasoning and application of values. Rights based perspectives provide an essential lens on structure, processes and relationships that support and govern children's lives; therefore, making a positive contribution to children's happiness, self-esteem and sense of agency. (Lee, 2005)

A rights-based perspective adds dimension but not made explicit in wellbeing discourses. It's taken as a given that wellbeing rights are automatically adhered, but often the intermediate space between home and public spheres, i.e. the Local Authority - in Bastian's case, the Local Authority being – The London Borough of Barnet) and school are key to wellbeing processes.

National Foundation for Educational Research for Children’s Commissioner England

CRAE – Children’s Rights Alliance for England

CHILDREN’S RIGHTS		
Rights	**Generation**	**Capacity**
Justice	Childhood	Competence
Incompetence	Adulthood	Care

Table: 1 - CRAE - Model of Children’s Rights

Universal Human Rights

Promotion of the Individual – Human rights are moral rights seen as universally relevant, unconditional and inalienable. They do not depend on the rights – holder undertaking particular responsibilities before they can be invoked. UNCRC (United Nations Convention on Rights of the Child)

Social Emotional Wellbeing

Wellbeing forms part of the Childs Rights, and SEWB (Social and Emotional Wellbeing) is the umbrella form for a wide range of concepts skills, dispositions and attitudes infused within the UK education Policy.

NICE (National Institute of Care Excellence) state: “SEWB encompasses; Happiness, Confidence and NOT feeling depressed”.

The ECM Agenda (DfES 2004a) National Healthy Schools Standard Promoting Emotional Health and Wellbeing (DFEE 2005) which is backed by the WHO (World Health Organisation – UNICEF, 2007) state: “Attention and focus needs to be on a child’s wellbeing and mental health within schools.”

SEAL – (Social and Emotional Aspects of Learning) Promoting Alternative Thinking Strategies PATHS (Paths Education Programme for Schools UK) UK Resilience Programme highlights the following:

- Feeling autonomy, control over one’s life
- **Ability to have good functional relationships with others to avoid disruptive behaviours**

Most alarming, as the research found out, Government and policy makers/drafters are evermore confused and unclear as to what emotional wellbeing entails. This is backed up by (Ereaut and Whiting), 2008; “Policy makers are unclear of what wellbeing is.”

The UN, WHO, the Organisation for Economic Co-Operation and Development (OECD) and the UN Educational Scientific and Cultural Organisation (UNESCO) has influenced UK Policy on SEWB in schools. Several Reports (UNICEFF, 2007) – Bradshaw Richardson, 2009, OECD 2009) suggest that UK children fare worse than their counterparts. A UNICEF Report surveyed 21 Rich Countries and ranked the UK a mere 17 out of 21. Therefore, the UK was bottom ranked in the EWB league table.

Moreover, moving to UNICEF 2010 – ‘The Children Left Behind’ – a league table of inequality in child wellbeing in the world’s richest countries – *Innocenti* Report Card 9; ranked the UK 13th out of 24 surveyed countries.

The *Innocenti Report Card* series is designed to monitor and compare the performance of economically advanced countries in securing the rights of their children.)

The *Innocenti* Report Card 11 (UK) – Presents a series clearly demonstrating that the legislative and policy decisions of governments have a significant impact on all children throughout their childhoods – particularly those living in poverty and disadvantage.

The UK has moved up the league table, but there is still a way to go to be near where we should be. More worryingly, the economic downturn is having a profound impact on the countries included in this research, many of which have seen rising unemployment and falls in public expenditure that inevitably will affect the lives of their children.

UNICEF Recommendations for Government Action in the UK

- Devise and support policies and programmes to close the gaps in child well-being, so that all children are given the opportunity to reach their full potential. UNICEF believes that more equal societies are better for children and everyone else. Inequality has the greatest impact on poor children and those living in the most deprived areas of society.

- Identify what resources are being invested in children. Child budgeting refers to the **identification**, **allocation** and **monitoring of resources spent on children** and **children’s services**. Being able to assess resource allocation is a necessary prerequisite to making better informed decisions about expenditure.

- Undertake regular analysis of the effects of decision making on children at **central** and **local government level**. The impact on children should be one of the first considerations of government before agreement on actions to reduce the deficit.

- Prioritise children's rights and ensure children's policy is more visible in and **across government**. Give one government department oversight of policies affecting children from 0 to 18/0-25 in SEND cases. Child well-being is multi-dimensional in nature and requires a coordinated response. Investment needs to be maintained from the early years through to young adulthood. (0-25 EHCP)

- Maintain the commitment to eradicate child poverty in the UK by 2020. A political focus on the poorest children in this time of exceptional financial pressure on families is at the heart of successfully protecting the most vulnerable in our society.

- Ask children how they feel about their lives. Under Article 12 of the UN Convention on the Rights of the Child, children have a **right to be asked** and a **right to be heard**. Adults have a responsibility to listen and respond to the thing's children say. As far as possible, adults must include children in the process of **determining and promoting** their own **well-being**.

Individual children pay the costs when we fail to safeguard their well-being but, over time, we all bear the costs. Making policy choices that lead to children suffering avoidable setbacks in the most formative stages of development is a breach of the most basic tenet of the UN Convention on the Rights of the Child – that every child has a right to develop to their full potential.

It is crucial to continue to closely monitor the state of children in the industrialized world, so as to prevent the heaviest burden of economic recession from falling on those least able to sustain it, and to avoid a slide from the achievements of the past decade.

The United Kingdom is placed 16th out of 29 countries in the new UNICEF league table of child well-being in the world's rich countries, and 86 per cent of UK children report a high level of life satisfaction. This represents a move up the table since the first UNICEF overview in 2007, when the UK was placed bottom out of 21 countries; but that improvement is not consistent across all areas.

It is still evident from the continued reports commissioned across the various organisations in the UK, that it's still failing its child citizens, and that children do not have a voice.

"For too many years, our society lived with a view that children should be seen and not heard. Without listening to children and understanding children's own views about their quality of life – how can we ever expect to improve the lives of children and young people" – Mathew Reed (Children's Society)

SEAL in the UK is still problematic as it operates children's emotional lives according to adult concepts.

Warnock (1978) developed the idea of Continuum of Need, where a continuum of needs requires a continuum of provision. Matching environments (the social) to individual needs (the bio) supports learning (the psycho).

Warnock goes on to say, about the 'Continuum' – allowing ALL children the culture of schooling (Gallagher; 2007). Therefore, the understanding of inclusive education is directly related to rights and differences.

Ellis et al; (2008) highlight inclusion of rights listed as:

- Ideology – Linked to Human Rights Agenda
- A place of School
- A policy
- Professional practice

The stimulation provided in a classroom is likely to be distracting. Further, independent behaviour displayed by students with severe disabilities is often not helpful for learning so that an organisations structure that is designed to encourage independence in the majority of students may be less appropriate for their needs.

Students with severe and or multiple disabilities as well as severe complex behaviours, still continue to be 'educated' in special programmes either in segregated classes or in schools within schools or in 'otherwise' units suffer the most as they are usually restricted to conforming to the less severe children, which is equally regressive for both mild and severe disabled students. Budget cuts and restraints on provision often place all disabled students together, expecting that students will automatically just get on. Not all disabilities are the same or equal; highlighting again that the voice of the child is not heard, and that inclusion is simply a tick box exercise.

Josephine Jenkinson states: "Inadequate accountability procedures have subsequently been revealed to result in considerable inequalities in the allocation of funding." (Resources and Funding: Trends and Practises – Mainstream and Special Schools)

Ability and Attainment

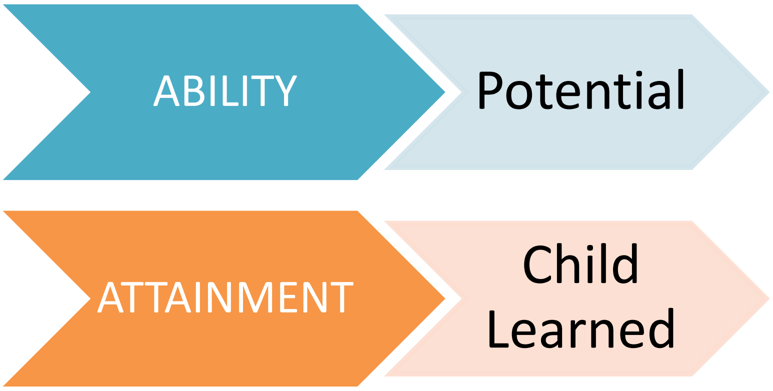


Fig: 1 - Ability and Attainment Model

United Nations Convention

United Nations Convention on the Right of the Child (1989) Children Act 1989 (Article 12) states: ***Childs views must be sought***

Children's self-esteem and self-knowledge are closely linked to the way in which they see themselves as learners. Their success as learners is dependent on them feeling secure and also having opportunities to experiment. Therefore, confidence is a catalyst in supporting personal growth.

An image of oneself as a distinct person is crucial in order to establish a sense of identity. Self-esteem is placed on value of identity. Self-esteem is not fixed and can fluctuate according to environment. Bastian's ability in seeing himself as 'normal' yet complex has been the biggest hurdle he has had to overcome both in terms of medical and psychological aspects of his life. That is why the lengthy process of researching various schools around the country has had to ensue.

The school best suited to his esteem, self-belief and personal views including his emotional stance was found in The Collett School. He expressed his views and stated: "At the Collett School, I felt really happy and did not feel like I was treated like a disabled boy, the atmosphere made me calm and excited for my big schools future". He expressed a distinct and explicit view on Oak Lodge School stating: "I felt more disabled at the Oak Lodge School and the feeling was frightening".

The above therefore highlights his view of self, which is a forward psychological progression step, which turn positively affected his emotional and mental wellbeing for a smoother secondary school transition, especially since he was going from a neuro-typical mainstream school to a special education needs secondary school.

Positive self-esteem on its own in not enough to base a case however linked with self-knowledge, the child has realistic views and optimisms of where he is best placed.

Living and Learning with Others

Children learn to relate to a wider group of adults and children when then move from security of home; however, in the wrong paced environment, children adapt to the norm, often following complex social skills which are against their self-knowledge, relaying and knocking their self-esteem. Therefore, the place of social skills needs to meet their self-knowledge and development.

Disabled children should have the possibility of ***Choice***. Policy makers and Educational Institutions or social organisation should make it possible for all children of any ability to make decisions based on how they see themselves through their self-knowledge.

Psychologists state that it is critical in allowing children who can think, to have a voice and to be heard. (Dowling, 2000) If the child is not heard, a state of disequilibrium ensues, which is the opposite of equilibrium; thus, when a child's previously held views or ideals are challenged, conflict can create a constant disequilibrium and a state of anxiety.

The Collet School offers a direct '*Emergent Curriculum',* which is a curriculum that arises from the child's interest and adults understanding the children's needs; they have de-institutionalised their schooling regime so as to create an environment that moves away from the 'one size fits all' approach.

> "Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid. ~ We therefore have to observe a fish in its natural environment to see it thrive" – Author Unknown - "An Educational Allegory" that was written under the pen name "Aesop, Jr." and published in the "Journal of Education" in 1898 could be the author who was later identified as Amos E. Dolbear of Tufts, a prominent physicist and inventor.

Researchers Edit: The Collett School was one of 45 schools researched, observed and visited, and upon entering the school and within the first 30 minutes of being shown around, Bastian's instinctive reaction was in expressing that this is the school where he felt most comfortable. He was allowed the freedom to express what it was that made him feel happy and comfortable, and he stated, "I feel normal here Mommy."

Bastian's mother including the head of The Collett School allowed him a choice, and a voice including being allowed to express, perceive and to feel without any intervention from professionals and or accompanying adults.

Emotional Wellbeing

People's emotional lives are increasingly seen as critical to their success in life. The link between feelings and brain development is important. Emotional abilities have been underrated in the role that they play in ensuring a successful and fulfilling life, regardless of intellectual capabilities.

Bastian is emotionally intelligent but intellectually disadvantaged by his neuro genetic disability. Gardner states: "Both rational and emotional abilities are now seen as being equally influential in determining achievement of Life."

Leuven scales for emotional well-being

Leuven scales for emotional well-being and involvement (developed by the Research Centre for Experiential Education at Leuven University, under the supervision of Professor Ferre Laevers) deliver *two* sets of indictors that should be considered when planning any educational setting (they are not designed solely for early childhood education but are equally applicable in primary, secondary, higher and adult education are detailed below:

Well-being focuses on the extent to which pupils feel at ease, act spontaneously show vitality and self-confidence. It is a crucial component of emotional intelligence and good mental health.

ONE - The Leuven Scale for Well-being

1. Extremely low
   The child clearly shows signs of discomfort such as crying or screaming. They may look dejected, sad, frightened or angry. The child does not respond to the environment avoids contact and is withdrawn. The child may behave aggressively, hurting him/herself or others.

2. Low
   The posture, facial expression and actions indicate that the child does not feel at ease. However, the signals are less explicit than under level 1 or the sense of discomfort is not expressed the whole time.

3. Moderate
   The child has a neutral posture. Facial expression and posture show little or no emotion. There are no signs indicating sadness or pleasure, comfort or discomfort.

4. High
   The child shows obvious signs of satisfaction (as listed under level 5). However, these signals are not constantly present with the same intensity.

5. Extremely high
   The child looks happy and cheerful, smiles, cries out with pleasure. They may be lively and full of energy. Actions can be spontaneous and expressive. The child may talk to him/herself, play with sounds, hum, sing. The child appears relaxed and does not show any signs of stress or tension. He /she is open and accessible to the environment. The child expresses self-confidence and self-assurance.

The rationale underlying focus on these two process dimensions is that high levels of well-being and involvement lead in the end to high levels of child development and deep level learning. This latter concept is centered around the notion that learning should result in significant changes in a pupils capacity leading to better outcomes in the way that he or she approaches work, relationships and life in general.

Level of involvement

Involvement focuses on the extent to which pupils are operating to their full capabilities. In particular it refers to whether the child is focused, engaged and interested in various activities.

TWO - The Leuven Scale for Involvement

1. Low Activity
   Activity at this level can be simple, stereotypic, repetitive and passive. The child is absent and displays no energy. There is an absence of cognitive demand. The child characteristically may stare into space. *N.B*. This may be a sign of inner concentration.

2. A Frequently Interrupted Activity
   The child is engaged in an activity but half of the observed period includes moments of non-activity, in which the child is not concentrating and is staring into space. There may be frequent interruptions in the child’s concentration, but his/her Involvement is not enough to return to the activity.

3. <u>Mainly Continuous Activity</u>
   The child is busy at an activity, but it is at a routine level and the real signals for involvement are missing. There is some progress, but energy is lacking and concentration is at a routine level. The child can be easily distracted.

4. <u>Continuous Activity with Intense Moments</u>
   The child's activity has intense moments during which activities at Level 3 can come to have special meaning. Level 4 is reserved for the kind of activity seen in those intense moments and can be deduced from the 'Involvement signals. This level of activity is resumed after interruptions. Stimuli, from the surrounding environment however attractive, cannot seduce the child away from the activity.

5. <u>Sustained Intense Activity</u>
   The child shows continuous and intense activity revealing the greatest Involvement. In the observed period not all the signals for Involvement need be there, but the essential ones must be present: concentration, creativity, energy and persistence. This intensity must be present for almost all the observation period.

<u>Measuring well-being and involvement</u>

The evaluation process begins by assessing the levels of well-being and involvement using the scales outlined above. Educators must observe pupils as a group or individually for a period of approximately two minutes then give a score for wellbeing and/or involvement. It is thought that unless pupils are operating at 4 or 5, learning will be limited. However, it is natural for levels of well-being and involvement to fluctuate throughout the day and it is therefore unrealistic to expect children to operate at levels 4 or 5 at all times.

The initial observation is the starting point for further analysis concentrating on pupils with lower levels of well-being and/or involvement. This analysis should inform educators about the quality and suitability of their work and it should provide some sort of framework for intervention toward individual pupils.

Measuring a child's wellbeing and involvement can also empower and energise teachers and practitioners. If educators can see that their efforts are leading to a high level of wellbeing involvement in their pupils then it's likely that this will serve as a galvanising force and result in a cycle of continual improvement.

The Research Centre for Experiential Education (RCEE) has produced a list of 10 action points that should help practitioners to focus the learning environment on the well-being and involvement of pupils:

Ten Action Points

1. Rearrange the classroom in appealing corners or areas
2. Check the content of the areas and make them more challenging
3. Introduce new and unconventional materials and activities
4. Identify children's interests and offer activities that meet these
5. Support activities by stimulating inputs
6. Widen the possibilities for free initiative and support them with sound agreements
7. Improve the quality of the relations amongst children and between children and teacher(s)
8. Introduce activities that help children to explore the world of behaviour, feelings and values
9. Identify children with emotional problems and work out sustaining interventions
10. Identify children with developmental needs and work out interventions that engender involvement

In addition to the action points Professor Ferre Laevers (director of the RCEE) highlights the importance of the way in which adults interact with children. He believes that this is key to the achievement of well-being and involvement and recommends the use of the Adult Style Observation Schedule (ASOS), which is made up of three components: stimulation, sensitivity and giving autonomy. Writing in an article published in the encyclopedia of early Childhood Development, Dr. Laevers defined the three components in the following terms:

"Stimulating interventions are open impulses that engender involvement, such as: suggesting activities to children, inviting children to communicate, asking thought-provoking questions and giving rich information. Sensitivity is evidenced in responses that witness empathic understanding of the child."

"Giving autonomy means respecting the children's initiative, acknowledging their interests, giving them room for experimentation, letting them decide upon the way an activity is performed and letting them participate in the setting of rules."

The EXE (www.exelearning.org) 'Ferre Laevers' definition of emotional well-being:

"The degree to which children do feel at ease can be spontaneous and are satisfied in, the physical needs, feel the need for tenderness and affection, feel the need for safety and clarity, the need for social recognition, the need to feel competent and the need for meaning in life and moral value."

Rees (1996) – (Reading Development Continuum) - Negative feelings can affect children's **working memory**, therefore affecting the work (psychologically and or educationally) already done to improve working memory by being in the wrong/adverse school placement.

1. *Seizing Opportunities for Emotional Learning*

When learning and talking about adults with emotional problems, the history can be traced right back to childhood, both within the family and schooling environments.

Thus, understanding a child's voice is critical for nurturing emotional growth. If an opportunity is missed simply by wrong placement in a mixed severe behavioural special school, it will become harder to progressively compensate the regression in later life; so therefore when looking at the factors for a specific institution or place, we need to include, place of education, climate of education and the environment of education; it is these very factors that establish a continuum of development. Therefore, providing an environment which enables children to acknowledge and express their feeling is directly attributed to positive emotional growth.

2. *Understanding about Being Equal*

As children develop a picture of themselves from a very early age and in direct relationships with family, this very same self-image continues when a child joins a group setting, they will attain how they are regarded by the wider group by social stances and or educational environments.

A vulnerable / different cognitive ability child placed in an adverse setting could unhinge his initial development. If children are already clear about their self-knowledge and voice but still placed in an adverse school placement, it could directly impair their future progress and happiness. It is in so far as to say that their belief in self is a key motivator to succeed in life.

Despite this awareness, the child's views are still not being addressed or even considered when being offered a SEN school placement.

Despite the much publicised and heightened awareness on the part of many; prejudice and discrimination is still carried out by Government, Local Authorities and official bodies when assessing and assuming that disabled children are ***one and the same***.

For the purposes of this report, the researcher states: evidence can be produced that construes a blatant manipulation of due process and a skewing of data so as to present and publish figures as 'fair and improving'; however to remain impartial the researcher will refer to this evidence as a ‘mistake’ as it is so often cited by Local authority representatives in assuming young children are immune from prejudice.

3. *Equality to Improve Educational Achievement*

A starting point to greater equality is to ensure all children have access to provision based on their individual needs. Provision is regarded optional, but parents and children’s views need to be recognised.

The future is always in the hands of children thus as respectful, moral and ethical citizens and human beings, we the human population need to prepare children in the best way possible.

> *“If you are thinking a year ahead; plant seeds, if you are thinking 10 years ahead, plant a tree. If you are thinking 100 years ahead – educate the people.”* Kuan-Tzu (4th - 3rd Century BC - China)
>
> Benjamin Franklin (1736) stated: “An ounce of prevention is worth a pound of cure.” (Firefighting advice on the prevention of fire), this quote went onto become the precursor for both the United Nations (UN) and The World Health Organisation (WHO).

Gerber, (2009) Prevention is Better than Cure - The UN and Human Rights Education:

Dr Gerber goes on to state: “It seems the United Nations (UN) similarly recognised that prevention is better than cure when it advocated, over 60 years ago, that “Education shall be directed to … the strengthening of respect for human rights.

The founders of the UN realised that it is far better to prevent human rights abuses occurring, than to try and ‘cure’ the problem, for example, by sending in peacekeepers after human rights atrocities have been committed.”

It can be argued that peacekeepers are the parents and or the few who stand up in fighting for their suffering children and the human rights atrocities that are being committed are being committed the Local Authorities or by government policy makers.

4. *Supporting the Vulnerable*

There is a caveat when making simple assumptions especially when complex needs must be met, Local Authorities must be careful in considering an individual, not just his/her disability, but rather authorities and professionals must take into account the entire individual and their abilities, including all psychosocial nuisances.

A CHILD’SSTATEMENT OF BELIEF

It is important for children to have opportunities to internalise the sense of belief within themselves.

Maslow’s Hierarchy of Human Needs (1943 – 1954)

- 1 - Self actualisation needs
- 2 - Self-esteem needs
- 3 - Social / affiliation / belongingness needs
- 4 - Safety needs
- 5 - Physiological needs

1 Developing talents
Personal fulfillment
Gaining recognition
Benefits others

2 Self-respect
Self confidence
Autonomy
Knowing one’s self or one’s talents

3 Friendships / Companionships
Group identity
Expressing oneself
Being understood
Caring

4 Security
Predictability
Safety against danger

5 Food
Shelter
Warmth
Sleep

BASTIAN’S STATEMENT OF BELIEF AND SELF-AWARENESS

Mommy: “Bastian, do you want to go to school?”

Bastian: “Yes, Mommy.”

Mommy: “Bastian, if you had a choice, and your voice was heard, and taking into account all the schools we went to visit, which school would you like to attend?”

Bastian: “The School in Hemel Hempstead Mommy, called The Collett School.”

Mommy: “Why have you decided on this school Bastian, can you explain?”

Bastian: “The Collett School makes me feel normal Mommy.”

Mommy: “Can you try to explain why this is Bastian?”

Bastian: “I like all people Mommy, it is just that this school makes me feel safe and happy and I can be myself without being scared, because I know myself and what I want.”

MY RIGHTS
Department of Health – UK Government:
Making Rights Better and Listening to People

> *‘My right to be listened to and have my wishes acted upon. My right to challenge decisions about me. Knowing your own rights and being involved. The right to say you think the wrong choice has been made and to ask for change.’*

Department of Health – UK Government:
No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.

Normal Lamb MP, states:

A lot has been done in treatment reviews of adults and children with learning disability, including new Acts and Legislative Processes; but, despite all of this, the scale or pace of change for individuals that we all wanted to see has not yet happened.

The right care in the right place - there should be real person-centred planning with the individual themselves at the heart. The system should be designed so that the incentives, processes and rules help people received the right care for them. This means the least ***restrictive*** setting possible, including real options for treatment at home and in the community.

Early intervention should be routine. In particular, some of the issues that people with learning disability or autism may face can become apparent very early in a child's life – sometimes as young as 18 months old. We want these children to be identified and offered support as early and effectively as possible so that no child or young adult ends up in long term inpatient or residential care because services didn't know how best to work with them. The need for **crisis response** should be seen as a warning about the local system's effectiveness at prevention.

Very clear accountability and responsibility throughout the system – there can be no excuses for a lack of clarity over responsibility or for people falling through the gaps between services. Integration and joint working between services are vital to giving people what they need. **But this needs to go hand in hand with clear accountability – and an end to passing the buck**.

Gavin Harding, MBE s states:

"I and everyone else with a learning disability hope to see this end and to start to see everyone with a learning disability or autism or with mental health needs being treated with respect and dignity equal to any other human being. We have the same rights as anyone else. After all, we are not just a label. We are not someone you can treat differently. We are human beings. We have an entitlement to a life just like you. Make the lives of all people with disabilities a good life without barriers. Take this opportunity to improve our lives – whoever is in Government. Let's not continue to repeat history and make the same mistakes."

Individual wellbeing, independence and inclusion - What has already been done?

The Care Act enshrines in law the individual wellbeing principle for care and support. It is the single unifying principle around which adult social care will in future be organised. The individual wellbeing principle incorporates key elements which are essential for inclusion in the community including social and economic wellbeing and participation in work, education, training or recreation. This means local authorities will now be under important duties in relation to these and other elements such as people's control of their day to day life, suitability of living accommodation and contribution to society. Importantly, local authorities are required to consider each individual's views, wishes, feelings and beliefs. This provides a focus on the outcomes that matter to people including inclusion and independence.

MY RIGHTS

My right to be Listened to and have my wishes acted upon and - My right to challenge decisions about me

Many pieces of legislation in recent years have strengthened people's rights. These include the Human Rights Act (1998) the Equality Act (2010) and the Mental Capacity Act (2005). The UK also ratified the UN Convention on the Rights of Persons with Disabilities and signed up to the '2010 WHO European Declaration on the Health of Children and Young People with Disabilities.

It is a core principle of the social care system that people themselves, often with the support of close friends, family and carers have the right to be involved planning their own care and support. This is enshrined in the Care Act (2014) which states "the importance of beginning with the assumption that the individual is best-placed to judge the individual's well-being" and the duty to have regard to "the individual's views, wishes, feelings and beliefs". Similarly, duties in the Children and Families Act (2014) require Local Authorities to have regard to the views, wishes and feelings of the child or young person and to enabling them to participate in decisions relating to themselves (or their child in the case of families).

It is very important to be clear that ***compulsory*** admission, treatment or detention, can ***only*** occur if the proper legal safeguards are applied, for example, under the relevant Mental Health Act or (1993 as amended 2007) in line with Mental Capacity Act provisions.

The recently revised Code of Practice for the Mental Health Act (1983 as amended 2007) strengthens statutory guidance where people are detained under the Mental Health Act to make sure that patients' views are taken into account as far as possible. This statutory guidance also requires professionals to take into account the choice of location and other factors raised by the patient and their family and requires them to be involved in decisions about renewals of detention. The Mental Health Act (1993 as amended 2007) and the Code also contain a number of points where people and their families can challenge decisions about their care.

However, as Sir Stephen Bubb said in his recent report:

> *"…the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored…… In some cases, people with learning*

> *disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights….in other cases, there are doubts over whether the rights of people with learning disability are being respected in practice as originally intended."*

We know that some people still have concerns about how much people are listened to. People have told us that the default is set the wrong way round. Statutory agencies and professionals should have to justify why, against the wishes of individuals or families, they are doing things like sending people away or keeping them away from their communities, homes, families or friends, whether to an inpatient or residential care setting. At the moment it can feel to families that the burden is on them to challenge and justify why this should not happen.

We are therefore interested in exploring how we strengthen the rights of the individual to challenge and choose and how the system is set up to support them to do this rather than to oppose them, as many people say is their experience. This includes whether there should be a stronger mechanism to enforce these principles in practice.

Knowing your own rights affords a responsibility for the NHS and Local Authorities to justify decisions about you. Because existing rights are complex and often poorly understood, 'we' want to ensure that, whether admitted under the Mental Health Act (1983 as Amended 2007) or not, people and their families are informed of their rights (and statutory agencies' duties) as soon as reasonably practical following the start of discussions about a potential admission – not once someone has been admitted.

This information sharing should continue throughout the inpatient stay up to and beyond discharge. At the moment there are a range of responsibilities under the MHA Code of Practise and the Care Act (2014) and elsewhere in relation to providing information to people and families but these are not brought together consistently in a single place for both the NHS and LAs. We suggest that this information has to be shared by a named professional (either a named social worker or an alternative agent/advocate of their own choice). As is already clearly required under the Equality Act (2010), it is vital that this is in a format that is accessible for the individual.

This information would form their own *personalised summary of rights* that are relevant to their individual circumstances – rather than a long potentially confusing or list of all potential rights which may or may not be relevant.

The individual and their family/carer (or other nominated advocate), should always be provided, by a named professional either a named social worker or alternate of their choice in a timely fashion with clear, easy read or accessible information by those responsible for overseeing these decisions.

This should be set out as: [The rights (and others' corresponding duties) which are relevant to their individual circumstance.]

CRAE

CRAE – Children's Rights Alliance for England, state:

Children's rights in England 2014: Children Bearing the Brunt of Austerity Cuts

Children in England are experiencing the hard edge of austerity, with mounting threats to their basic human rights. The cumulative impact of cuts to services, the cost of living crisis, and changes to the welfare system, means some children in England are not having their basic needs for shelter and food met and can't access the services which are supposed to support families, while many more are not able to enjoy a fulfilled and happy childhood.

On the eve of the 25th anniversary of the blueprint for children's human rights – the UN Convention on the Rights of the Child - the 12th **State of Children's Rights in England** (2013) report reveals that as a result of struggling services and squeezed families too many children are having their basic human rights breached.

The annual report, compiled by the Children's Rights Alliance for England (CRAE 2014), draws on hundreds of sources and responses to Freedom of Information requests to examine how children and young people are faring in all aspects of their lives.

Paola Uccellari, Director of CRAE said,

"Children's rights are the basic things children need to thrive - the right to an adequate standard of living, to an education, to be cared for and to play. Children's rights should act as a safety net – meaning children always receive minimum standards of treatment whatever the changing economic climate.

Every child has a human right to a good start in life – an equal chance to do well at school, to be healthy and to be safe and cared for. Yet when you lay out the issues facing children in England in 2014, you cannot escape the conclusion that austerity and cuts to vital services are threatening children's human rights. If a child is living in poverty, if they don't have enough food and their family can't afford suitable housing then their physical health, mental health and educational attainment all suffer.

Services which make sure children's human rights are met – which support families, provide childcare, play schemes and youth groups - aren't a luxury. They are essential to giving children a good start in life, to children's ability to develop confidence and resilience and even to keeping children safe and well. They mean parents can work and are able to care for their children, and that children have a safe place to meet and play. Cutting these services is short-sighted; it will have a long-term impact on children and society."

Children have a human right to a fulfilling childhood and to develop to their full potential but the services which support this have been hit hard.

- Across England there has been a 54% decrease in local authority funding for play between 2008-09 and 2014-15, with 3 local authorities who responded to CRAE's Freedom of Information request reporting their budget for play had reduced to zero this year.
- Responses to CRAE's Freedom of Information request show that many local authorities have reduced their youth services budget by an average of 35% (as a proportion of local authority spending) between 2008-09 and 2014-15.

Disabled children are particularly vulnerable when services are cut.

A lack of financial and practical support for disabled children and their families mean that disabled children are not being properly supported to go to mainstream schools, are excluded from local services and recreational opportunities and, in some cases, their families are at breaking point, with children even entering care because of their disabilities.

- Only 28% of local authorities have enough childcare suitable for disabled children and only between 4% and 6% of disabled children are accessing youth services.
- The proportion of children with Special Educational Needs (SEN) attending special, rather than mainstream schools, increased from 37.5% to 40.5% between 2009 and 2014, and children with SEN made up the vast majority of children excluded from school (62%) in 2012-13.
- In 2013-14, for 3% of looked after children their "category of need" was their disability.

Emotional Needs and Learning

In order to develop a structure of personal meaning which sustains development, we need an environment conducive of emotional safety. (Emotional Growth and Leaning, Greenhalgh, 1994)

EDUCATIONAL IMPLICATIONS

Emotional Development and emotional Intelligence

Peter Salovey, David Sluyter – 1998

Psychological Model and Neural Models

How compatible is the psychological model of development with Neurobiology?

Direct links at neuronal levels are still being explored, recent advances in developmental neuropsychology provides striking psychological parallels to psychological observations with regard to emotional development and linking it to language and cognitive function.

Frontal lobes of the brain play an increasing role in emotional development. The brains functioning within the context of social and emotional Learning

The Brain has 3 main layers, these three parts of the brain do not operate independently of one another, they have established numerous interconnections through which they influence one another, through neutral pathways.

- Neocortex
- Limbic System
- Reptilian System

Neocortex

Neocortex relates to both left and right hemispheres.

Left: Analyses over time

Right: Synthesises Space

Thus, the Neocortex communicates and works together, enabling a two way react/response pathway. However, as Bastian's '*Corpus Callosum*' is damaged, tangled and underdeveloped or rather since he has a *Dysengenic Corpus Callosum* (DCC)

- DCC/ACC - Agenesis and or Dysengenic Corpus Callosum is a rare neurological condition where the corpus callosum is underdeveloped. The corpus callosum is a bridge of white matter joining the two cerebral hemispheres (left and right sides) of the brain. White matter consists of nerve fibers surrounded by a type of fat called myelin, which gives the whitish appearance to the white matter. The corpus callosum forms during the brain development when a baby is in the womb. People usually only find out there is total or partial absence of the corpus callosum with brain imaging tests and these will usually only be performed if individuals have neurological problems that suggests something may be wrong with the nervous system or brain. So there

> may be people without symptoms that have partial or complete Callosal Agenesis (loss of white matter from the corpus callosum).
>
> (Medical text written November 1998 by Dr L Rosenbloom, Consultant Paediatric Neurologist, Alder Hey Children's Hospital, Liverpool, UK. Last updated May 2012 by Dr KRE Pohl, Consultant Paediatric Neurologist, Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust, London, UK.)

Since Bastian's brain structure is diagnosed with DCC, he struggles with speed of processing, and or difficulties in the absorption/retention of information. However, the complexities of Bastian don't stop there, his DCC is and can be managed, the further complexity is that in addition to his ACC, he was finally diagnosed after an 8-year research period with an extremely rare genetic disorder; $SETD_5$.

It is this or rather the DNA (deoxyribonucleic acid) and RNA (ribonucleic acid) strands that are damaged and missing which attribute to his differentiated neurological functioning's, resulting in a plethora of deeper neurological, psychological, physical and intellectual disabilities (ID). [$SETD_5$ will be discussed in detail, further along in this report].

New research is also beginning to uncover the ways in which early experiences may impact the brain to develop long term emotional responding. As discussed in this report, it is now evident to state that ***environment is imperative*** to building emotional and mental well-being; therefore Bastian's home, social, cultural, physical and past educational environmental exposures which he has already developed, including building up a stable and strong sound self-acknowledging emotional well-being life style, needs to be kept at a continuum.

The Limbic System

The Limbic System supports a variety of functions which are responsible for emotions, motivations, behaviours, olfaction and long-term memory. The limbic system carries the central sight for emotion within the brain, which in Bastian's case is fully formed and functioning at a higher intellect that most peers of his age. His olfaction is exceptionally acute in the acknowledging/sensing smells from a far often resulting in an onset of 'headaches' were the smell to be overpowering. His long-term memory is extremely heightened by his use of event triggers and his power of recall is his strength. However, his working/short term memory (Short term memory acts as a note pad to temporary recall information, which is being processed at any given time is severely affected on an hourly and daily basis.) This short-term memory 'pad' is located in the central executive part of the prefrontal cortex at the front of the brain which plays a fundamental role in all short term and working memory processes. Although Bastian Limbic system is formed and functioning, a small lobe is in default in part due to his ACC however in parts also down to SETD$_5$; therefore, making Bastian one of the most complex human beings.

The Reptilian System

The Reptilian brain, the oldest of the three, controls the body's vital functions such as heart rate, breathing, body temperature and balance. Our Reptilian brain includes the main structures found in a reptile's brain: the brainstem and the cerebellum.

Although Bastian's Reptilian system is fully formed and intact, the neocortex pathways interfere with his reptilian layer, however only at critical points, which is partially down to his DCC but more importantly caused by SETD$_5$, resulting in pathways that allow certain bodily functions to operate indifferently causing at times physiological difficulties. The frontal lobe is the emotional manager, and as Bastian's lobe is intact, his emotional pathway is fully operational.

NEUROLOGY AND GENETICS AFFECTING BASTIAN WILLICOTT (12yrs 11mnths)

Parents: Bastian lives in England with Mother, has minimal if any contact with Father who lives in Greece.

Mother: Healthy Female – **No** predisposed hereditary genetic mutations affecting biology or neurology/possible (ID).

Ethnicity - Maternal - European German lineage to South Africa
Paternal - European British lineage to Zimbabwe
Self - European mixed genetics born Zimbabwe

Father: Healthy Male – **Possible** predisposed non hereditary genetic encoding affecting neurology.

Ethnicity - Maternal - European (Mediterranean) Greek Island
Paternal - European (Mediterranean) Greek Island

Pregnancy: First trimester - Near miscarriage (5 Previous Miscarriage)

Second trimester - Stable, with risk testing factor resulting 1 in 10 - Possible Abnormality
Third trimester - Emergency C-section – with Apgar test normal scoring, physiological genitalia abnormality noted

0 to 2yrs: Stable, with delayed onset of milestones, sleeping difficulties, feeding difficulties and toileting difficulties, speech difficulties

MOTHER PUSHED FOR INVESTIGATIVE REPORTS

2 to 4yrs: Bastian known as an enigma - complexities and intelligence as combined factors, resulting in skewed results

<u>Part of the various Testing’s</u>

- Audiology (Hearing abnormality)
- Ophthalmology (Stable normal functioning)
- Cardiology (Stable walls, intact, with erratic murmur displacement, environmental tachycardia)
- Anatomy & Physiology (growth normal, features abnormal, low and poor muscle tone, genitalia abnormal, dysmorphic facial features, deglutition abnormality)
- Speech & Language (complexity, in processing with dysfluency)
- Occupational Grouping (Complex)
- Physical Grouping (Complex)
- Dental (Combination of normal and short-term abnormality)
- Abdominal (Rectal dysfunction)
- Neurology (Complex)
- Psychology (Severe & Mild / Normal with complexities – skewed results Weiner/British Abilities et al. – Uneven profile Mild Learning Disability to Low Average)

  “If Bastian has a cognitive assessment as part of the research work that has diagnosed his rare condition, then this assessment should be also examined. As it stands there is some minor variance between the research paper describing the features of Bastian’s rare condition and the findings of the Psychological clinic of the last 6 years. It is clear that Bastian’s condition is a rare and an unusual mix of strengths and difficulties” Mark Carter (2014).

- Urology (Reconstruction – complex)
- Genetics (Complex skewed results)
- Social (Mild, Neutral, Intelligent Complexities)

- Education (1:1, Learning disability, complexity in accessing numeracy/literacy all round cognition)
- Specialist OT (Proprioception, Vestibular, Gross & Fine Motor Abnormalities Sensory Perception & Processing difficulties, Visual Cognition variations)

Bastian has a very rare and complex mix of abilities, intelligences (academic, emotional, mental and psychological) coupled with a plethora of abnormalities and difficulties, which he can equally and simultaneously experience; thus ticking all the ‘tick box thresholds’ and yet none simultaneously, particularly when analyzing and providing advises on specialist provision.

MOTHER UNDERTOOK RESEARCH WHILST PUSHING FOR ALL LOCAL, NATIONAL AND INTERNATIONAL RESEARCH ORGANISATION TO INVESTIGATE BASTIAN WHICH INCLUDED ASKING MEDICAL AND TEACHING UNIVERSITIES FOR INDEPTH DIAGNOSTIC GENETIC TESTING.

4 to 10yrs: Bastian finally accepted by World Wide Genetics Programme – yielded no results.

Bastian finally accepted by Cambridge and Oxford University on rare disease studies programme.

Bastian formally, medically and legally diagnosed November 2013 (8 years after first mother pushed for Genetic Testing.
(De Novo Loss of Function Mutations in SETD$_5$, encoding a Methyltransferase in a 3p25 Microdeletion Syndrome Critical region, Cause intellectual Disability)

Bastian’s findings published (27 March 2014) in The American Journal of Human Genetics Volume *94 – Grozeva, D. Canham, N. Raymond, F Lucy.)*

Bastian finally diagnosed with SETD$_5$ Rare (one of six)
Bastian finally diagnosed with DCC (Dysengenic Corpus Callosum) (Great Ormond Street Hospital London, Neurology Dept. 2012) – making Bastian the only one of the world with this rare combination (Current 2017). [Current 2019]

10 to 13yrs: Bastian has been awarded a placement on a further Genetic Follow Up study with Cambridge University Research Department (Department of Medical Genetics) called SPEED (Specialist Pathology Evaluating Exomes in Diagnostics, including the BINGO Programme (Brain

Institute – Cambridge Genetics and Medical Department) and IMAGINE ID 1000 Study by Lucy Raymond.

This project aims to achieve an immediate data resource - BioResource –Rare Diseases: so as to develop more affordable DNA-based tests for the diagnosis of rare diseases for which the gene is known.

This is the first whole exome sequence project to be trialled recruiting directly from referrals to NHS clinical genetics centres for a diagnostic test. Results of this study will inform a step change in diagnostics for rare diseases in the UK. Data generated from this project will inform strategic planning of genetics services in the near- and longer-term future (5-10 years).

Together this project will pilot the delivery of whole exome data to NHS patients where currently:

1. Sequential diagnostic testing of specific candidate genes is likely to be more expensive and slower than a whole exome approach.
2. Multiple screening for a diagnosis by biochemical assays of different tissues is more expensive and time consuming than screening the exome as a first line specialist investigation.

For this study the Cambridge Team have collaborated with Illumina, Inc. to develop analytical tools with this data set and will develop algorithms to trial in clinical service with a view to developing a commercial product that could be useful for diagnostics and communication to patients and relatives. This will be relevant to all users of diagnostic exomes in clinical practice in the future.

Recruitment Criteria:

There are two areas of recruitment to SPEED:

Paediatric neurology/metabolic disease

Up to 50% of all paediatric admissions are associated with an underlying genetic condition. However, the process of establishing a specific diagnosis is often slow, logistically laborious and expensive requiring serial cross-disciplinary investigations. For paediatric neuro-metabolic diseases early diagnosis is likely to improve outcome, help families cope with the diagnosis and provide access to therapeutic options of early blood stem cell transplantation or enzyme replacement in certain cases, which have proven better outcomes if initiated early in life.

SETD 5

De novo loss of function mutations in SETD5, encoding a Methyltransferase in a 3p25 microdeletion syndrome critical Region, cause intellectual disability – sequence analysis DNA

Raymond et al – 2014

Histone methyltransferase - Two major types of histone methyltranferases exist, lysine-specific (which can be SET (**S**u(var)3-9, **E**nhancer of Zeste, **T**rithorax) domain containing or non-SET domain containing) and arginine-specific.

ID – Intellectual Disability

De Novo Loss – Not inherited – Occur by chance

Phenotyping can currently not be transcribed as apart from the 7 individuals who had a similar craniofacial feature.

SETD5– Enzyme Coding Protein critical for fundamental brain function – D – Dopamine 5 (Receptor 5). Cause ID - Intellectual Disability previously known as Mental Retardation.

To identify further Mendelian causes of intellectual disability (ID), a screening of a cohort of 996 individuals with ID for variants in 565 known or candidate genes by using a targeted next-generation sequencing approach. Seven loss-of-function (LoF) mutations—four nonsense (c.1195A>T [p.Lys399*], c.1333C>T [p.Arg445*], .1866C>G [p.Tyr622*], and c.3001C>T [p.Arg1001*]) and three frameshift (c.2177_2178del [p.Thr726Asnfs*39], c.3771dup [p.Ser1258Glufs*65], and .3856del [p.Ser1286Leufs*84])—were identified in SETD5, a gene predicted to encode a methyltransferase. All mutations were compatible with de novo dominant inheritance.

The affected individuals had moderate to severe ID with additional variable features of brachycephaly; a prominent high forehead with synophrys or striking full and broad eyebrows; a long, thin, and tubular nose; long, narrow upslanting palpebral fissures; and large, fleshy low-set ears. Skeletal anomalies, including significant leg-length discrepancy, were a frequent finding in two individuals. Congenital heart defects, inguinal hernia, or hypospadias were also reported. Behavioral problems, including obsessive-compulsive disorder, hand flapping with ritualized behavior, and autism, were prominent features. SETD5 lies within the critical interval for 3p25 microdeletion syndrome.

The individuals with SETD5 mutations showed phenotypic similarity to those previously reported with a deletion in 3p25, and thus loss of SETD5 might be sufficient to account for many of the clinical features observed in this condition. The findings add to the growing evidence that mutations in genes encoding methyltransferases regulating histone modification are important causes of ID. This analysis provides sufficient evidence that rare de novo LoF mutations in SETD$_5$ are a relatively frequent (0.7%) cause of ID.

It is to be noted that Bastian has had an MRI which determined his DCC. No other families have reported DCC; thus, leaving Bastian as the only one out of the cohort study with this rarity, with no other published cases to date.

IDENTIFYING AND MODELLING GENES, THAT ARE ASSOCIATED WITH RARE DEVELOPMENTAL DISORDERS – SETD5

Keren Jacqueline Carss

2014

Rare genetic disorders often have a classical Mendelian pattern of inheritance, and they are often caused by a single high-penetrance variant. There are at least 6000-7000 rare genetic disorders, meaning that collectively they are in fact common, and the causes of around half have been identified thus far. While numerous different phenotypes are associated with rare genetic disorders, they often affect development, and first manifest *in utero*, in infancy, or in childhood.

There are two reasons why the study of rare developmental disorders is of great importance. First, it directly improves the lives of patients and their families. Occasionally, identification of the genetic cause of a disorder will lead to improved treatment or a new therapy for a patient. It also often allows patients and their families to access additional social and educational services, and it can allow estimation of recurrence risk for future pregnancies.

Families affected by a rare developmental disorder often go through a ‘diagnostic odyssey’ that can last a decade or more, during which many different individual medical and genetic tests are performed in an attempt to identify the cause of the disorder. Therefore, finally receiving a genetic diagnosis can bring great peace of mind, even if it would not influence treatment.

The second reason to study and report rare developmental disorders is that they often give insights into relevant biological processes, and into the aetiology of more common forms of disease. This has been recognised for centuries. In 1657 Dr William Harvey observed that “there is no better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of nature by the careful investigation of cases of rarer forms of disease.”

The impact of intellectual disability

Intellectual disability (ID) is diagnosed in patients who have an intelligence quotient (IQ) of below 70, along with problems with adaptive functioning (such as problems communicating or caring for themselves), where these symptoms began before the age of 18. ID is typically classified as mild (IQ 50-70) or severe (IQ below 50) although other categories can be used. It is phenotypically heterogeneous; in addition to variable IQ and different manifestations of problems with adaptive functioning, it often occurs in conjunction with other abnormalities, such as seizures, behavioural difficulties, dysmorphic facial features, or other developmental disorders such as congenital heart disease (CHD). A particularly common comorbidity of ID is autism spectrum disorder (ASD), with 28% of people with ID also suffering from ASD.

ID with additional comorbidities is often classified as ‘syndromic’, and cases with no additional symptoms are ‘non-syndromic’. However, recent opinion in the ID research community has shifted away this dichotomous categorisation, in favour of considering ID as a spectrum, with variable additional phenotypes. This is partly because subtle comorbidities or specific intellectual disabilities shared among groups of patients are often not obvious until they are retrospectively grouped according to aetiology.

Collectively, ID is a very common developmental disorder, with a prevalence of around 1-2%, but estimates of prevalence vary widely depending on factors including the definition of ID, the population studied, and age group. Importantly, the prevalence also depends on sex, with males accounting for 57% of ID cases. The majority of patients with ID require extensive medical, financial and personal support throughout their lives, causing ID to be one of the most costly diseases in high-income countries. Because ID is so prevalent, it therefore has a profound impact not only on patients and their families, but also on healthcare providers and society as a whole.

The causes of ID are wide ranging and include environmental and genetic factors. Environmental factors that are associated with increased risk of ID include malnutrition during infancy, prenatal exposure to alcohol or the rubella virus, childhood exposure to lead, brain injury during birth, and low birth weight. Foetal alcohol syndrome affects 0.1-0.7% of births and is the most common preventable cause of ID in high-income countries. With this exception, environmental factors disproportionately affect people in low-income countries, and explain the increased prevalence of ID in such countries.

Genetic causes of ID have been recognised for many decades. Lionel Sharples Penrose was the first to conduct a large study on the subject, which was published in 1938. He assembled and investigated a cohort of 1280 cases of ID. His pioneering observations included the sex bias in prevalence of ID, and the fact that related patients often have similar phenotypes. Historical studies such as this, draw attention to two relevant ethical issues.

First, ID, possibly more than any other medical condition, uses terminology that has evolved. In Penrose’s study, for example, patients are classified according to whether they are “dull”, “simpletons”, “imbeciles” or “idiots”. By 1960, these offensive terms had been replaced in the medical and research communities by the term mental retardation. Gradually, this term too attracted derogatory connotations, and in 2009 a law (known as Rosa’s law) was passed in the USA officially replacing it with the term intellectual disability.

Second, early studies of the genetics of ID are tainted by their unpleasant association with the eugenics movement. For example, in “The Eugenics Review”, Eliot Slater describes aspects of Penrose’s study to be “of profound eugenic significance”. J. B. S. Haldane, commenting on Penrose’s study in Nature, took a moderate approach, emphasising the complexity of the aetiology of ID, and calling the claims that it could be largely eliminated by sterilisation of patients to be “extravagant”.

From these beginnings, research into the genetics of ID and intelligence has flourished. Intelligence is a quantitative trait and is highly heritable. Mild, non-syndromic ID represents the bottom of the normal distribution of IQ, and these cases are likely to be influenced by multiple genetic and environmental factors each with a small effect size as for any quantitative trait. To start to understand the genetic architecture of these cases will require genome-wide association studies with extremely large sample sizes. However, moderate to severe ID is thought to be usually caused by a ***single pathogenic variant with a large effect***. Identification of these variants and understanding how they cause ID is of great importance.

Case-control enrichment analysis of rare variants

Rare disease-associated genes are usually identified by means of a classical, case-only diagnostic approach, where they are identified because they contain rare, coding variants which segregate with disease in multiple families, for example. Case-control enrichment analysis is a supplementary method that can yield additional insights into the aetiology of rare disease. Typically, a cohort of cases is assembled, along with a cohort of controls. Rare variants are identified in both cohorts (for example by exome sequencing), and then a statistical test is applied to test the hypothesis that the cases have an excess of a defined category of variants compared to controls.

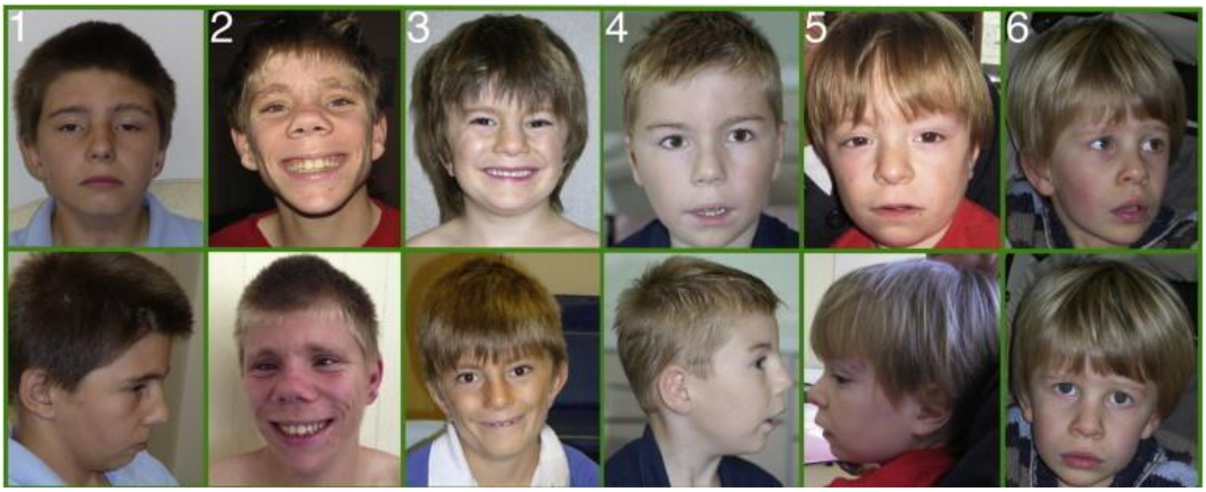
Case-control enrichment analysis can yield insights into the genetic architecture of a rare disease without necessarily assigning causality to individual variants. It can be used with a range of study designs, whereas classical approaches often require very specific study designs. For example, to identify *de novo* mutations DNA samples from both biological parents are required, which are not always available. Perhaps most importantly, case-control enrichment analysis makes fewer assumptions about causative variants than classical approaches, and therefore takes into account non-classical contributors to disease such as variants with incomplete penetrance, and variants that contribute to a phenotype in an oligogenic manner.

$SETD_5$ is a novel intellectual disability-associated gene

To identify novel ID-associated genes, Dr Lucy Raymond and Dr Detelina Grozeva focused on genes that had the highest number of LOF variants in the list that ID generated. They found that seven individuals had a rare, high-quality, LOF variant in $SETD_5$ (0.7% of the cohort). They confirmed all the variants using Sanger sequencing and confirmed that five are *de novo* by Sanger sequencing of parental DNA (paternal DNA was unavailable for two probands).

An international team of collaborating clinicians documented and compared the phenotypes of the seven patients with $SETD_5$ mutations. In addition to ID, there were several common and recurring features including ritualised behaviour or ASD, abnormal ears, eyebrows, eyes, and nose, and skeletal and gastrointestinal abnormalities. They noticed that the facial appearance of the cases was, in some aspects, strikingly similar (See Photo Image 3). Due to the phenotypic similarity of the cases, and the small probability of this many mutations occurring by chance, we concluded that these LOF mutations in $SETD_5$ are causative in these six/seven patients, and that LOF of $SETD_5$ causes a potentially recognisable syndrome. Indeed, LOF of $SETD_5$ may be a relatively common cause of ID.

BASTIAN WILLICOTT – Photo Image 3



There are three reasons why $SETD_5$ was selected as a candidate ID-associated gene to be sequenced in this study. First, a *de novo* LOF mutation in $SETD_5$ was reported in a single ID patient in a previous study. While intriguing, this was not sufficient for Rauch *et al.* to conclude that $SETD_5$ is definitely an ID-associated gene, and the authors did not extensively report the phenotype of this patient. Second, *de novo* $SETD_5$ mutations have been associated with ASD in several studies, and it is widely known that there is much overlap in the presentation and genetic aetiology of ID and ASD. Third, $SETD_5$ is one of only two protein-coding genes in the minimal critical region for 3p25 microdeletion syndrome.

The 3p25 microdeletion syndrome was first described in 1978. Since then there were several other case reports of *de novo* deletions at this locus, resulting in phenotypes including ID, seizures, microcephaly, CHD, malformed ears and nose, and other dysmorphic craniofacial features. The sizes and breakpoints of the deletions in these cases varied, and so the minimum critical region was refined over time. Most recently, a case report refined it to only 124 kb, containing only three genes: *THUMPD3*, *SETD*$_5$ and *LOC440944* (an RNA gene).

Therefore, it is also important to apply statistical tests to demonstrate that the variants in question are significantly enriched in patients. Furthermore, if LOF variants in a given gene are relatively common in the general population it is unlikely that LOF of that gene causes a rare disease. Several ID-associated genes have recently been called into question on this basis.

Therefore, in this study, Raymond and her colleagues took care to apply a high standard of evidence to the data, before concluding that *SETD*$_5$ is a novel ID-associated gene. For example, we showed that LOF of *SETD*$_5$ in the general population is very rare, and we showed that the mutations identified were highly unlikely to have occurred by chance.

SETD$_5$ is predicted on the basis of sequence homology to encode a histone methyltransferase (205). As well as *SETD 5* and *EHMT1* (pathogenic variants in which can cause Kleefstra syndrome as discussed) known ID-associated histone methyltransferases include *EZH2* and *MLL2* (also known as *KMT2D*). EZH2 is part of a complex that methylates a specific lysine residue on histone H3. It has many important roles in development, including X chromosome inactivation, and stem cell regulation (207, 208). *De novo* mutations in *EZH2* can cause Weaver syndrome, features of which include ID, overgrowth, and characteristic craniofacial dysmorphic features. *MLL2*, mutations in which can cause Kabuki syndrome, which also involves ID, and also catalyses methylation of histone lysine residues.

Therefore, although little more is known about the function of *SETD*$_5$, histone methyltransferases are clearly emerging as a very important class of ID-associated genes. *SETD*$_5$ fits well into the known pattern for ID-associated histone methyltransferases, because all known causative mutations are *de novo*, and the resulting phenotype is syndromic. These two features are consistent with all the other known examples of ID-associated histone methyltransferases discussed.

BASTIAN WILLICOTT – *SETD*$_5$ AND DYSENGENIC *CORPUS CALLOSUM* PHENOTYPIC EXPRESSIONS

Corpus Callosum - *The corpus callosum is important in timing tasks, attention, motor tasks, and coordination. When the corpus callosum fails to develop properly a* *person tends to have problems with attention, which is needed to perform cognitive (thinking) tasks, including reading and writing, the underdeveloped corpus callosum will result in poor motor coordination, and even mental retardation. Importantly, these defects in brain function can occur even when facial abnormalities are not present. The corpus callosum develops throughout gestation. (Great Ormond Street Hospital)*

Dysengenic *Corpus Ccallosum* *(D**CC**) is a rare birth defect (Congenital Disorder) in which there is a complete or partial absence / underdevelopment of the corpus callosum. It occurs when the corpus callosum, the band of white matter connecting the two Hemispheres in the brain, fails to develop normally, typically during pregnancy. The development of the fibers that would otherwise form the corpus callosum become longitudinally oriented within each hemisphere and form structures called Probust Bundles.*

In addition to agenesis of the corpus callosum, the other colossal disorders include hypo genesis (partial formation), Dygenesis (malformation) of the corpus callosum, and hypoplasia (underdevelopment) of the corpus callosum.

Signs and symptoms of DCC/ACC and other colossal disorders vary greatly among individuals. However, some characteristics that are common in individuals with colossal disorders include vision impairments, low muscle tone hypotonia, poor motor coordination, delays in motor milestones such as sitting and walking, low perception of pain, delayed toilet training, and chewing and swallowing difficulties.

Laboratory research has demonstrated that individuals with DCC/ACC have difficulty transferring more complex information from one hemisphere to the other. They also have been shown to have some cognitive disabilities (difficulty in complex problem solving) and social difficulties (missing subtle social cues), even when their intelligence quotient (IQ) is normal. Recent research suggests that specific social difficulties may be a result of impaired facial processing.

The unusual social behavior in childhood is often mistaken for or misdiagnosed as Asperger syndrome or other autism spectrum disorders. Other characteristics sometimes associated with colossal disorders include seizures, spasticity, early feeding difficulties and/or gastric reflux, hearing impairments, abnormal head and facial features, and a mental handicap.

SETD$_5$

Intellectual Disability - Intellectual disability *is a* **disability** *characterized by significant limitations in both* **intellectual** *functioning and in adaptive behaviour, which covers many everyday social and practical skills. This* **disability** *originates before the age of 18 and is set for life. (Great Ormond Street Hospital & Cambridge Human Genetic and Medical Centre)*

Gastrointestinal and/or Abdominal-wall anomalies – *Bastian is unable to know when to toilet, rather than train Bastian, his mother has trained his bowels and urinary tract as per muscle memory contractionary movement analysis, on-going interventions. Diet is strictly supervised etc. [http://www.ncbi.nlm.nih.gov/pubmed/1386985]*

Congenital Heart Defects – *Bastian has a heart murmur, and environmental Tachycardia – his heart valves are intact and monitored****.***

Scoliosis or Kyphosis – *Bone/spine vertebrae – although Bastian's back is of typical structure and composition, he has a 'webbed neck' [Pterygium colli deformity]; which makes for the neck structure short in appearance and function - muscles not as flexible when moving, especially when using the head in a left and right function, up/down function – causing a substantial degree of difficulty and immobility.*

Dysphagia - Feeding difficulties – *Those with SETD$_5$ often are associated to having a* ***swallowing disorder****, also called* **dysphagia** *can occur at different stages in the swallowing process Bastian has a high risk of choking, where the muscles and neuro signals from the brain do not filter through. He has been in A&E on numerous occasions for a serious choke; last serious dysphagia episode was in 2015 – blue lighted to hospital, 2 minutes without breath, obstruction on food. The is an emergency plan in place and Bastian is now aware that he has to chew and slowly, drink slowly and his food his left in whole states or finely chopped and water is thickened with heavier fluid particles so as to aid swallowing function; he has been taught to be fully aware of the choking attack, and how to implement calming strategies and what to do in these circumstances. He experiences 1 – 2 attacks per month; the process is becoming more manageable and controlled.*

Postaxial Polydactyly – *(EXTRA Fingers / toes) although Bastian does not present this presence - he has what is called webbed fingers and padded finger tips, making fine gross motor skills more difficult.*

Thin Upper Lip – *Genetic physiology.*

Long, smooth, and/or Prominent Philtrum – *The vertical groove between the base of the nose and the border of the upper lip, the junction between the two halves of an homo sapiens / animal's upper lip or nose; genetic physiology.*

Abnormal Nasal Shape – *As part of genetic expression - unaffected - breathing and typical nasal function intact.*

Depressed Nasal bridge – *Low Nasal Bridge caused by genetic physiology. The underlying causes of a low nasal bridge are present at birth, diagnosed at or shortly after birth. Underlying causes include genetic disorders, birth defects, and infectious disease.*

Upslanting or Downslanting Palpebral Fissures – *The **Palpebral Fissure** is the elliptic space between the medial and lateral canthi of the two open lids. In simple terms, it refers to the opening between the eye lids. In adults, this measures about 10mm vertically and 30mm horizontally; Bastian details fissure as part of the* $SETD_5$ *phenotypic expression.*

Ritualized Behaviours /Autism – *Phenotypic expressions could be correlated to that of autistic like behaviours, these can be observed on a daily basis, e.g.; movements, sleeping ritualization's/obsessions, mini seizure like episode, hand/chest flapping or bashing, etc. It must be highlighted that Bastian does not have autism. (Edgware Community Hospital)*

Brachycephaly – *This is when the back of the skull/head becomes flattened, causing the head to widen. To compensate, the front of the skull sometimes bulges out, or the forehead is enlarged. Some* $SETD_5$ *individuals have moderate frontal cortex defects; however, the frontal cortex pertaining to Bastian remains intact.*

Hearing Abnormality Low-set and/or Malformed Ears – *Pinna abnormalities and low-set ears Pinna abnormalities and low-set ears refer to an abnormal shape or positioning of the outer ear (pinna or auricle).*

The outer ear or "pinna" forms when the baby is growing in the mother's womb. The growth of this ear part takes place at a time when many other organs are developing (such as the kidneys). [Bastian has both hearing and kidney-urinary tract difficulties].

Abnormalities in the shape or position of the pinna may be a sign that the baby also has other related problems. Bastian has significant hearing loss in the ***<u>left ear</u>*** *and is under the NHS. (Oak Lane Audiology Clinic)*

Synophrys and/or Abnormal Eyebrows - *A unibrow (or monobrow; called synophrys in medicine) is the presence of abundant hair between the eyebrows so that they seem to converge to form one long eyebrow, evidenced by Bastian facial physiology.*

Hypospadias – (On-going Clinical and Surgical Interventions)
Male Genitalia congenital birth malformation) (Complete reconstruction of penile tubing and meatus aged 1, continued urology interventions including a urology psychologist is in situ.) Bastian’s bladder and urinary tract has been rained, which in turns allows for minimal prompting when toileting. Organ anatomy training via muscle memory was implemented as a training tool rather than the standardised physical training routines. (Great Ormond Street Hospital)

Hypospadias refers to a birth defect of the urethra within male, where the urinary tract or opening has not formed at the correct locality on the head of the penis. It is the second most common birth abnormality in boys, affecting approximately 1 of every 300. In approximately 90% of cases, the opening (meatus) is on or near the head of the penis (glans), referred to as distal hypospadias, while the remainder have proximal hypospadias with a meatus near or within the scrotum. The sheeny tissue seen extending from the meatus which should have made the urinary channel can be referred to as the urethral plate. Bastian has Proximal Hypospadias II.

Orthodontia Abnormalities – *Hypo Mineralisation and Hypodontia*
Dentistry – has had several operations and will have on going interventions. Molar incisor ***hypo mineralization*** *(MIH) is a common developmental condition resulting in enamel defects in first permanent molars and permanent incisors. It presents at eruption of these teeth. One to four molars, and often also the incisors, could be affected. Bastian also presents with hypodontia [tooth agenesis] – missing permanent adult teeth. (Eastman’s Dental Hospital& UCLH London))*

Speech and Language – *Language delay and/or stammer*
Language delay and/or stammer from neurological processes and or memory retrieval anomalies have as the causal effect on the speech dysfluency. Speech therapy or speech dysfluency therapy aids the neurological signalling. The dysfluency is spikey, dependant on the neurological functioning on a day to day basis. (NHS Vale Drive Speech and language Clinic)

Psychology – Cognitive – *Bastian is under CAMHS/Barnet SCAN for on-going Cognitive and Psychoanalytical therapy.*

MAKING HEADWAY WITH GENETIC DIAGNOSTICS

Intellectual disability or mental retardation, what is in a name?

Willemsen and Kleefstra

2014

In the Journal of Clinical genetics; Wiley J. & Sons (2014:85:101-110) states: “In 2006, the American Association on Mental Retardation (AAMR) changed the name to the American Association on Intellectual and Developmental Disabilities (AAIDD). Furthermore, in October 2010, President Obama signed ‘Rosa’s Law’, mandating that the term ‘mental retardation’ should be replaced by ‘intellectual disability’ in the federal statutes. It has created confusion, as opponents state it is not accurate in so far as to say, intellectual disability is not a development problem.

‘The above statement could be argued as correct, as Bastian although diagnosed with intellectual disability, is developing at four levels,1) above average,
2) neurotypical 3) below average 4) severe.

The WHO (World Health Organisation) bases ID diagnostics – or by definition by AAIDD. The definition comprises three criteria:

(i) A significant limitation in intellectual functioning
(ii) A significant limitation in adaptive behaviour
(iii) An origin before the age of 18 years

Knowing the cause of ID is of great importance. It may provide insight in co-morbidity, associated behaviour and thereby gives answers to important questions, for families, health care providers and professionals. Identification of a genetic cause precludes further constant and unnecessary and often incriminating testing and fruitless interventions.

Mongenic causes

Dominant ID – Severe AD ID is almost always of *de novo* origin. It is assumed that *de novo* copy number variations and point mutation may explain severe ID. As Bastian has *de novo*, he is seen as severe, yet because of the critical layers within the brain function that also remain intact, he is even more complex; thus, offering skewed analysis of dual severity and intelligence.

It is because of this skewed dual double exceptionality and contradiction in terms, that Bastian’s clinical analytical psychoanalyst has stared collating data on Bastian in order to publish critical phenotyping and associated behaviours on psychological, emotional and intellectual outputs, so as to offer a better understanding for all possible future cohorts and or professional provisions within Cognitive and behavioral genetics. As of 2014, Professor Raymond of Cambridge University’s Genetics Department has implemented the further reporting of new scientific studies to measure and or collate phenotypic expressions on those with SETD$_5$.

Cognitive and behavioral genetics

EFFICIENT STRATEGY FOR THE MOLECULAR DIAGNOSIS OF INTELLECTUAL DISABILITY USING TARGETED HIGH-THROUGHPUT SEQUENCING; BMJ (2014)

Intellectual disability (ID) is a common neurodevelopmental disorder reported in 1.5–2% of children and adolescents. ID is defined by significant limitations in both intellectual functioning and adaptive behaviour with onset before the age of 18. Different classes of ID are conventionally defined upon IQ values (severe or profound, <35; moderate, 35–49 and mild, 50–70). However, in routine genetic practice, clinical assessment mainly based on records of developmental history, speech acquisition and patients’ autonomy is used for classification in such subcategories. Causes of ID can be environmental, genetic or multifactorial.

Single genetic events are thought to account for a majority of cases, varying from large chromosomal anomalies or copy number variants (CNVs) affecting several genes to point mutations in single genes. These latter monogenic forms are characterised by an extreme genetic heterogeneity, with a hundred genes described as implicated in X-linked ID (XLID) and more associated to autosomal-recessive or autosomal- dominant forms. Altogether there are more than 500 genes proposed to cause ID with high penetrance when mutated underlying a phenotypic heterogeneity of the same extent in both severity and associated symptoms.

CEREBRAL CORTEX ADVANCE ACCESS

DOPAMINE, SALIENCE, AND RESPONSE SET SHIFTING IN PREFRONTAL CORTEX

Shiner, et al.

2014

Dopamine is implicated in multiple functions, including motor execution, action learning for hedonically salient outcomes, maintenance, and switching of behavioural response set. Here, they used a novel within-subject psychopharmacological and combined functional neuroimaging paradigm, investigating the interaction between hedonic salience, dopamine, and response set shifting, distinct from effects on action learning or motor execution.

Wellcome Trust Centre for Neuroimaging, Institute of Neurology, asked whether behavioural performance in response set shifting depends on the hedonic salience of reversal cues, by presenting these as null (neutral) or salient (monetary loss) outcomes. They observed marked effects of reversal cue salience on set-switching, with more efficient reversals following salient loss outcomes. L-Dopa degraded this discrimination, leading to inappropriate perseveration.

Generic activation in thalamus, insula, and striatum preceded response set switches, with an opposite pattern in ventromedial prefrontal cortex (vmPFC). However, the behavioural effect of hedonic salience was reflected in differential vmPFC deactivation following salient relative to null reversal cues. L-Dopa reversed this pattern in vmPFC, suggesting that its behavioural effects are due to disruption of the stability and switching of firing patterns in prefrontal cortex.

Their findings provide a potential neurobiological explanation for paradoxical phenomena, including maintenance of behavioural set despite negative outcomes, seen in impulse control disorders in Parkinson’s disease. Shifting from one pattern of behavioural response to a more appropriate action in the face of unexpected or surprising events is central to adaptive behaviour.

Dopamine is implicated in shifting response set, including triggering of a behavioural switch (Cools, Lewis et al. 2006; Lee et al. 2007), learning new associations (Shohamy et al. 2005), maintenance of learned associations (Cohen et al. 2002), commission of action (Frank et al. 2004), and both tracking and responding to rewarding or punishing (i.e., hedonic or valenced) outcomes in decision making (Cools et al. 2009; van der Schaaf et al. 2014).

Several brain regions, all of which receive strong dopaminergic innervation, are thought to support this process, including medial and lateral prefrontal cortex as well as the striatum (Fellows and Farah 2003; Izquierdo et al. 2004; Robinson et al. 2010; Rygula et al. 2010; Hampshire et al. 2012; Fallon et al. 2013).

It has been suggested that aberrant attribution of salience to cues is central in obsessive–compulsive disorder, addiction and depression (Diekhof et al. 2008), as well as in the impulse control disorders observed in Parkinson’s disease (Dagher and Robbins 2009). However, dopaminergic modulation has mixed effects on these processes. For example, in learning from negative feedback in patients with Parkinson’s disease, dopamine can improve performance in some domains but exerts a detrimental effect on others (Cools et al. 2003; Frank et al. 2004; Shohamy et al. 2005, 2006; Shiner et al. 2012).

Here, they sought to delineate the role of dopamine on the shifting of response set in healthy individuals, and specifically how this depends upon the hedonic salience (e.g., negative valence) of outcomes.

[The researcher hypothesises that the above may be the critical information needed so to establish and to keep intact a continuum of environment thus avoiding a possibility of Bastian regressing into abnormal behavioural patterns and or regressing into a ‘depression’, as per the physiological reports have suggested; thus his self-esteem would suffer were he placed in an environment not suitable or unsuitable to and by his own reported self-awareness.]

One standard view of dopamine—namely the reporting of reward prediction errors—is based on an assumption that subjects need to learn the value of subsequent actions (Schultz et al. 1997; Daw and Doya 2006; Niv and Schoenbaum 2008).

Importantly, the employed a task in which stimulus–response–outcome mappings were deterministic (in contrast to most reversal paradigms where mappings are probabilistic), such that unexpected outcomes triggered a switch in response set rather than new learning, which is also dopamine-dependent. In this context when subjects have already learned response contingencies, reinforcement learning about actions has limited utility. Instead, subjects have to infer changes in contingencies before selecting the appropriate set. In this setting, dopamine may have a complimentary role in reporting the precision or confidence in beliefs about the consequences of action under the current set (Galea et al. 2012).

Unexpected outcomes following an action engender a striatal signal, reflecting a prediction error thought to emanate from the nigrostriatal dopamine system. Here, we predicted a corresponding reduction in prefrontal responses, due to uncertainty about current set, would be modulated by mesocortical dopaminergic inputs (Friston et al. 2012). This concurs with increases in striatal blood oxygenation level-dependent (BOLD) signal seen following salient outcomes such as reward omission (Pagnoni et al. 2002), or negatively valenced events such as loss or punishment on the one hand (Cools et al. 2002; Seymour et al. 2005) and, on the other hand, phasic decrements in BOLD signal following the unexpected absence of a reward in the context of a well-established stimulus–outcome train, in dorsal (Ramnani et al. 2004) and ventral (O'Doherty et al. 2003) regions of medial prefrontal cortex. Moreover, we asked whether prefrontal responses to unexpected outcomes would similarly depend upon the hedonic salience of outcome cues.

Previous findings from their laboratory have highlighted functional asymmetries in probabilistic learning requiring commission or omission of responses, respectively (Guitart-Masip, Huys et al. 2012), and widespread regions of prefrontal cortex are differentially activated by action versus action inhibition (Rubia et al. 2001; Criaud and Boulinguez 2013). Note here, they, were interested in distinguishing dopaminergic effects on set-switching separate from its effects on action execution. To control for differences in movement, they alternated between "go" and "no-go" response sets which enabled them to average over behavioural and physiological responses that did, and did not, involve executive motor components (and nonspecific behavioural inhibition), thereby isolating set-switching per se.

A key finding under placebo was that subjects were highly skilled at rapidly altering their behaviour following unexpected outcomes but were significantly less successful at reversal switching when these reversal cues were less salient.

[Adaptive survival mechanisms, conferred by evolutionary selective pressures, are necessarily tuned to avoidance of salient loss and, in this context, it is unsurprising to find such a striking asymmetry in behaviour conditional on the hedonic salience of an outcome.] The pattern of behaviour under placebo is in stark contrast to what they observed following administration of L-dopa—where an advantage in behavioural switching response to salient cues was lost. This implies that L-dopa degrades the discrimination between a salient loss and a neutral null outcome.

This echoes observations that action reprogramming in response to surprising events is dependent on optimal levels of **dopamine**, and that disorders of dopaminergic transmission can lead to impairments in shifting behavioural set (Berke and Hyman 2000; Hampshire et al. 2012; Galea et al. 2012). Moreover, on L-dopa we observed a trend toward reversal of the normal pattern of behaviour, with better reversal switching in response to null outcomes—consistent with evidence that increasing dopamine selectively stabilizes striatal representations of a correct behavioural response for rewards in a Go/ No-Go task (Guitart-Masip, Chowdhury et al. 2012) and the observation that dopamine has a differential influence on rewarding compared with punishing outcomes (van der Schaff et al. 2014).

Dopamine has a central role in the maintenance of patterns of neuronal firing in widespread regions of prefrontal cortex (Durstewitz et al. 1999; Seamans and Yang 2004).

For example, there is a well-characterized dopaminergic influence on the representational capacity of working memory mediated via an effect on delay-period activity in dorsolateral PFC (Sawaguchi and Goldman-Rakic 1991; Floresco and Phillips 2001; Fuster 2001). More generally, the prefrontal cortex has been suggested to maintain patterns of activity corresponding to behavioural relevant actions and goals (Miller and Cohen 2001). For example, ventrolateral PFC contains neuronal populations coding for stimuli, actions and behavioural context (Asaad et al. 2000).

Neurons with task-selective delay-period activity are also present in medial prefrontal cortex (Sakurai and Sugimoto 1986; Baeg et al. 2003), which may underpin the maintenance of appropriate reward-based action–outcome contingencies (Phillips et al. 2004; Deco and Rolls 2005; Floresco et al. 2005; Winter et al. 2009).

The researcher highlights the following unexpected outcomes – which back up the Psychoanalysis reports on Bastian:

[*This latter mechanism predicts that unexpected outcomes should lead to a reduction in dopaminergic modulation of prefrontal cortex, allowing escape from one pattern of neuronal attractor dynamics to an alternative pattern, facilitating a reversal switch (O'Reilly et al. 2002; Deco and Rolls 2005).*

This strongly indicates that vmPFC is attuned to maintenance of behavioural set contingent on hedonically salient outcomes (i.e., rewarding or punishing) over and above sensitivity to generally surprising outcomes. Dopaminergic disruption selectively obliterates this intrinsic sensitivity to valenced outcomes, although overall behavioural performance is maintained, and this is suggestive that modulation by L-dopa may lead to aberrant attachment of salience to non-salient outcomes. In healthy individuals, intrinsic dopamine levels are likely to be optimized.]

Given that the innate salience of negative outcomes is also likely to reflect a well-tuned behavioural adaptation, it is perhaps unsurprising that the/our dopamine manipulation obliterated this normal sensitivity to loss.

In conclusion, they showed an effect of salience on set switching; with more efficient reversal following unexpected losses compared with null outcomes was abolished by L-dopa, both at the level of behavior and associated prefrontal responses. Context sensitive processing requires an intact interplay between various cortical and subcortical regions that form the brains reward circuits which is impacted by alteration of endogenous dopamine levels in the brain (Diekhof et al. 2008).

This alteration in a balance between the impact of hedonically salient, compared with neutral, outcomes might underlie a range of phenomena, including the bias in salience attribution to cues observed in the depressive state, addiction (Diekhof et al. 2008) and Tourette syndrome (Gilbert et al. 2006) all of which implicate dysfunction in dopaminergic pathways.

It might also explain common clinical syndromes such as pathological gambling, where there is a lack of avoidance of negatively reinforced actions and impulse control disorders in Parkinson’s disease (Evans et al. 2004), where a blunting or reversal of the normal suppression of activity might explain a paradoxical maintenance of behavioural set in the face of negative outcomes.

THE PHYSIOLOGY, SIGNALING, AND PHARMACOLOGY OF DOPAMINE RECEPTORS

Beaulieu and Gainetdinov

2011

G protein-coupled dopamine receptors (D1, D2, D3, D4, and D5) mediate all of the physiological functions of the catecholaminergic neurotransmitter dopamine, ranging from voluntary movement and reward to hormonal regulation and hypertension.

Pharmacological agents targeting dopaminergic neurotransmission have been clinically used in the management of several neurological and psychiatric disorders, including Parkinson’s disease, schizophrenia, bipolar disorder, Huntington’s disease, attention deficit hyperactivity disorder (ADHD1), and Tourette’s syndrome. Numerous advances have occurred in understanding the general structural, biochemical, and functional properties of dopamine receptors that have led to the development of multiple pharmacologically active compounds that directly target dopamine receptors, such as antiparkinson drugs and antipsychotics.

Recent progress in understanding the complex biology of dopamine receptor-related signal transduction mechanisms has revealed that, in addition to their primary action on cAMP-mediated signaling, dopamine receptors can act through diverse signaling mechanisms that involve alternative G protein coupling or through G protein independent mechanisms via interactions with ion channels or proteins that are characteristically implicated in receptor desensitization, such as arrestins.

One of the future directions in managing dopamine-related pathologic conditions may involve a transition from the approaches that directly affect receptor function to a precise targeting of postreceptor intracellular signalling modalities either directly or through ligand biased signalling pharmacology.

In this comprehensive review, they went on to discuss dopamine receptor classification, their basic structural and genetic organization, their distribution and functions in the brain and the periphery, and their regulation and signal transduction mechanisms. In addition, we discuss the abnormalities of dopamine receptor expression, function, and signalling that are documented in human disorders and the current pharmacology and emerging trends in the development of novel therapeutic agents that act at dopamine receptors and/or on related signalling events.

Since the discovery of the physiological functions of 3-hydroxytyramine (dopamine), a metabolite of the amino acid tyrosine, more than 50 years ago (Carlsson et al., 1957), this catecholaminergic neurotransmitter has attracted an enormous amount of attention. In a similar manner to other monoamine neurotransmitters, dopamine generally exerts its actions on neuronal circuitry via a relatively slow modulation of the fast neurotransmission that is mediated by glutamate and GABA. Dopaminergic innervations are the most prominent in the brain.

Four major dopaminergic pathways have been identified in the mammalian brain; the nigrostriatal, mesolimbic, mesocortical and tuberoinfundibular systems that originate from the A9 (nigrostriatal), A10 (mesolimbic and mesocortical, often collectively termed the mesocorticolimbic pathway), and A8 (tuberoinfundibular) groups of dopamine-containing cells (Anden et al., 1964; Dahlstroem and Fuxe, 1964), respectively.

These neurons are critically involved in various vital central nervous system functions, including voluntary movement, feeding, affect, reward, sleep, attention, working memory, and learning.

[In the periphery, dopamine plays important physiological roles in the regulation of olfaction, retinal processes, hormonal regulation, cardiovascular functions, sympathetic regulation, immune system, and renal functions, among others (Snyder et al., 1970; Missale et al., 1998; Sibley, 1999; Carlsson, 2001; Iversen and Iversen, 2007). Because dopamine is involved in a variety of critical functions, it is not surprising that multiple human dis- orders have been related to dopaminergic dysfunctions.]

Dopamine dysregulation is expected to occur in ADHD and Tourette's syndrome (Mink, 2006; Swanson et al., 2007; Gizer et al., 2009). The abnormal plasticity of reward mechanisms that has been shown to be associated with drug abuse and addiction strongly suggests that dopamine plays an important role in this pathological condition (Hyman et al., 2006; Di Chiara and Bassareo, 2007; Koob and Volkow, 2010). A role for abnormal dopaminergic signaling has also been suggested for a host of other brain disorders, such as bipolar disorder, major depression, dyskinesias, and various somatic disorders, including hypertension and kidney dysfunction (Missale et al.,1998; Aperia, 2000; Carlsson, 2001; Iversen and Iversen, 2007).

Once released from presynaptic terminals, dopamine activates members of a family of G protein-coupled dopamine receptors named D1 to D5. Targeting these receptors using specific agonists and antagonists has provided an opportunity to significantly influence dopaminergic transmission and dopamine-dependent functions by enhancing or blocking the actions of dopamine.

In addition to significant progress in understanding the structural, genetic and pharmacological properties of dopamine receptors, more recent studies have begun to uncover the complexity, intricacy, and plasticity of intracellular signaling mechanisms that are involved in dopamine receptor functions.

This knowledge has led to the development of new paradigms to understand the role of dopamine receptors at a system level. Such frameworks can provide an opportunity to comprehend multilevel interactions between dopamine and other extracellular messengers, such as glutamate, serotonin, or neurotrophins, in the control of mechanisms through which dopamine affects gene expression or long-term synaptic plasticity.

Furthermore, this approach can define the contribution of aberrant processes or genetic defects that are not obviously associated with dopaminergic neurotransmission to the pathogenesis of dopamine related disorders and point to the specific intracellular processes that should/could be targeted by future pharmacological approaches.

Because of the large body of literature on dopamine receptor gene organization, structure, and expression profiles that has been reviewed extensively in several excellent review articles (Niznik and Van Tol, 1992; Sibley and Monsma, 1992; Sokoloff et al., 1992a; Civelli et al., 1993; Missale et al., 1998; Vallone et al., 2000; Seeman, 2006; Rankin et al., 2010), they cover these topics only briefly in section II.

Instead, they focused on the recent progress toward understanding the molecular mechanisms that are involved in dopamine receptor regulation and signaling that could provide novel targets and approaches for pharmacological intervention in dopamine-related disorders.

Dopamine Receptors: Classification, Genes, Structure, Expression, and Functions

Basic Genetic and Structural Properties of Dopamine Receptors

The physiological actions of dopamine are mediated by five distinct but closely related G protein-coupled receptors (GPCRs) that are divided into two major groups: the D1 and D2 classes of dopamine receptors (Andersen et al., 1990; Niznik and Van Tol, 1992; Sibley and Monsma, 1992; Sokoloff et al., 1992a; Civelli et al., 1993; Vallone et al., 2000). This classification is generally based on the original biochemical observations showing that dopamine is able to modulate adenylyl cyclase (AC) activity.

In addition to these functional receptors, two pseudogenes have been described for the human D5 dopamine receptor that encodes truncated non-functional receptor forms (Grandy et al., 1991). It is commonly accepted that the D1-class dopamine receptors (D1 and D5) activate the G_s/olf family of G proteins to stimulate cAMP production by AC and are found exclusively postsynaptically on dopamine-receptive cells, such as GABA-ergic medium spiny neurons (MSNs) in the striatum.

D1-class dopamine receptors have several distinct characteristics in their genetic and structural properties.

Dopamine Receptor Expression

D5 dopamine receptors are expressed at low levels in multiple brain regions, including pyramidal neurons of the prefrontal cortex, the premotor cortex, the cingulated cortex, the entorhinal cortex, substantia nigra, hypothalamus, the hippocampus, and the dentate gyrus. A very low level of expression has also been observed in the MSNs of the caudate nucleus and nucleus accumbens (Missale et al., 1998; Gerfen, 2000; Sokoloff et al., 2006; Rankin et al., 2010).

Dopamine Receptor Functions

Because dopamine is critically involved in a number of physiological processes, the functional roles of the different dopamine receptor subtypes have been extensively characterised. The most studied role involves the effects of dopamine on locomotor activity.

The roles of D4 and D5 dopamine receptors, which have a limited expression pattern in the primary motor regions of the brain, seem to be minimal in the control of movement (Missale et al., 1998; Sibley, 1999; Rondou et al., 2010). At the same time, D3, D4, and, potentially, D5 dopamine receptors seem to have a minor modulatory influence on some specific aspects of cognitive functions that are mediated by hippocampal areas (Missale et al., 1998; Sibley, 1999; Sokoloff et al., 2006; Rondou et al., 2010).

In general, the specific physiological roles played by D3, D4, and D5 dopamine receptors in the brain remain largely unknown.

General Principles of Dopamine Receptor Signal Transduction and Regulation Mechanisms of G Protein-Mediated Signaling

All dopamine receptors belong to a large superfamily of GPCRs. Dopamine receptors show a high degree of similarity in their primary amino acid sequences, have a common structure of seven transmembrane-spanning domains and are capable of activating heterotrimeric G proteins to induce intracellular signaling mechanisms (Gingrich and Caron, 1993; Missale et al., 1998; Neve Et al., 2004)

Finally, the COOH terminal domain of the D5 dopamine receptor has been shown to interact with the second intracellular loop of the GABA-A _2- receptor subunit in the rat hippocampus (Liu et al., 2000). It is noteworthy that the interaction of dopamine receptors with GABA-A receptors seems to be specific to the D5 dopamine receptor, because this interaction does not occur for the D1 dopamine receptor.

Pharmacology of Dopamine Receptors and Human Diseases

Abnormalities in Dopamine Receptor Physiology in Human Disorders

Numerous studies have focused on abnormalities in dopamine receptor biology as an underlying cause of mental disorders. Understanding the role of dopamine receptors in human diseases began with the development of receptor binding techniques that provided an opportunity to measure dopamine receptor binding characteristics in post-mortem tissues of patients with various disorders (Seeman and Van Tol, 1994). However, after multiple attempts, it has become obvious that receptor density measurements provide an extremely variable picture of the alterations that are likely to reflect particularities in post-mortem tissue collection rather than underlying pathological mechanisms.

D_5 DOPAMINE RECEPTOR

D_5 Dopamine Receptor Knockout Mice and Hypertension

Yang et al.

2004

Bastian suffers from environment adrenal tachycardia - adverse environments increase his heart rate to dangerous levels often over 102bpm; therefore, placing Bastian in an unsuitable environment based on his perception and self-knowledge, could increase his risk. This can be discussed and expressed by the D_5 Dopamine Receptor Knockout Mice and Hypertension research paper.

“Dopamine is an endogenous neurotransmitter catecholamine that also serves as a biochemical precursor of norepinephrine and epinephrine. During the past decade, however, dopamine has been recognized as an important regulator of blood pressure, sodium balance, and adrenal, intestinal, and renal function. Dopamine exerts its actions via two families of cell surface receptors that belong to the rhodopsin-like family of G-protein-coupled receptors (GPCRs). D_1-like receptors are composed of the D_1 and D_5 subtypes.

Abnormalities in dopamine production and receptor function have been described in human essential hypertension and rodent models of genetic hypertension. All of the five dopamine receptor genes (D_1, D_2, D_3, D_4, and D_5) expressed in mammals and some of their regulators are in loci linked to hypertension in humans and in rodents.

The D_5 receptor, like the D1 receptor, is expressed in renal proximal and distal tubules, cortical collecting ducts, and tunica media of arterioles; the thick ascending limbs of Henle may preferentially express the D5 receptor over the D1 receptor.

Renal cortical D5 expression, like D1 receptor expression (see above), is similar in hypertensive and normotensive rodents and humans (unpublished). As stated earlier, there are no ligands that can distinguish the D5 from the D1 receptor, but the D5 receptor has a higher affinity for dopamine than the D1 receptor and exhibits some constitutive activity. D5 receptor genes are not linked to hypertension in Dahl salt-sensitive rats, and mutations of the D5 receptor are not found in the SHR.

However, the D5 receptor gene locus (chromosome 4p15.1–16.1) is linked to essential hypertension. Moreover, the human D5 receptor gene has polymorphisms that code for receptors with abnormal coupling to adenylyl cyclase.

Over activity of the sympathetic nervous system (SNS) causes acute and chronic elevations of blood pressure through hemodynamic effects, alterations of renal sodium and water handling, and induction of cardiac and vascular remodelling. Several neuropeptides, especially angiotensin II, interact with the sympathetic nervous system. In conclusion, the disruption of the D_5 dopamine receptor gene increases blood pressure in mice.

The elevated blood pressure is suggested to be caused by increased sympathetic tone by activation of central oxytocin, V1 vasopressin, and non-NMDA receptors. The contribution of the kidney in the hypertension associated with deletion of the D_5 receptor gene remains to be determined."

CEREBRAL CORTEX ADVANCE ACCESS

DOPAMINE D_1/D_5 RECEPTORS MEDIATE INFORMAL SALIENCY THAT PROMOTES PERSISTENT HIPPOCAMPAL LONG-TERM PLASTICITY

Niels Hansen, Denise Manahan-Vaughan

2012

Dopamine [DA] plays an essential role in the enablement of cognition. It adds colour to experience-dependent information storage, conferring salience to the memories that result. At the synaptic level, experience-dependent information storage is enabled by synaptic plasticity, and given its importance for memory formation; it is not surprising that [DA] comprises a key neuromodulator in the enablement of synaptic plasticity, and particularly of plasticity that persists for longer periods of time: Analogous to long-term memory.

The hippocampus, which is a critical structure for the synaptic processing of semantic, episodic, spatial, and declarative memories, is specifically affected by [DA], with the D_1/D_5 receptor proving crucial for hippocampus-dependent memory.

Furthermore, D_1/D_5 receptors are pivotal in conferring the properties of novelty and reward to information being processed by the hippocampus. They also facilitate the expression of persistent forms of synaptic plasticity and given reports that both long-term potentiation and long-term depression encode different aspects of spatial representations, this suggests that D_1/D_5 receptors can drive the nature and qualitative content of stored information in the hippocampus. In light of these observations, we propose that D_1/D_5 receptors gate hippocampal long-term plasticity and memory and are pivotal in conferring the properties of novelty and reward to information being processed by the hippocampus.

Dopamine [DA] is a neurotransmitter in the central nervous system that belongs to the catecholamine’s (Carlsson et al. 1962). [DA] neurons are categorized in dopaminergic systems based on their innervation territories. Four axonal dopaminergic pathways are described: 1) nigrostriatal, 2) mesolimbic,
3) mesocortical, and 4) tuberoinfundibular (Vallone et al. 2000).

[DA] subserves a multitude of roles in rognition-related brain functions: It regulates memory, motivation, mood, motor activity, and neuroendocrine integration (Horn et al. 1979; Fluckiger et al. 1987) and is released after novel (Ljungberg et al. 1992), salient sensory (Ungless 2004), aversive (Bromberg-Martin et al. 2010), or reinforcement-relevant (reward) stimuli (Schultz et al. 1993).

For many decades, its role in cognitive disorders and brain disease has been intensely studied. This derived from observations that a strikingly low [DA] concentration occurs in the basal ganglia of patients with Parkinson's disease (Ehringer and Hornykiewicz 1960) and that [DA] dysfunctions contribute to cognitive disorders such as schizophrenia (Goto and Grace 2007; Lodge and Grace 2011), drug addiction (Robinson and Berridge 1993), attention deficit hyperactivity disorder (Del Campo et al. 2011), and possibly Alzheimer's disease (Kumar and Patel 2007; Jürgensen et al. 2011). Experimental evidence suggests that [DA] is highly relevant for the modulation of hippocampus-dependent synaptic plasticity and memory (Jay 2003; Lisman and Grace 2005; Lisman et al. 2011). These effects are mediated by 2 distinct groups of [DA] receptors:

The D_1/D_5 (D_1-like) receptors and the D_2-like receptors (Tiberi et al. 1991; Vallone et al. 2000; Beaulieu and Gainetdinov 2011) (Fig. 1), whereby, in recent decades, the D1/D5 receptors have received increasing attention. This is because of the significant role that they play in the regulation of both hippocampus-dependent synaptic plasticity (the mechanisms believed to underlie learning) and hippocampus dependent memory (Huang and Kandel 1995; Lemon and Manahan-Vaughan 2006; Bethus et al. 2010; Clausen et al. 2011; Da Silva et al. 2012).

Activity-dependent alterations in synaptic strength encode new information in the brain. Two major forms can be distinguished: 1) long-term potentiation (LTP; Bliss and Lomo 1973; Bliss and Collingridge 1993) and 2) long-term depression (LTD) of synaptic strength (Dudek and Bear 1992; Manahan-Vaughan 1997).

Both phenomena are believed to underlie hippocampal learning and memory (Bliss and Collingridge 1993; Bear 1996; Kemp and Manahan-Vaughan 2007). This likelihood is supported by more recent studies that address a phenomenon known as '***learning-facilitated plasticity***'.

Studies of learning-facilitated plasticity suggest that LTP and LTD are responsible for the encoding of different elements of a memory representation. Thus, LTP is associated with the encoding of global space, spatial change, or contextual fear (Straube et al. 2003; Kemp and Manahan-Vaughan 2004; Whitlock et al. 2006), whereas LTD is associated with the encoding of spatial context (Manahan-Vaughan and Braunewell 1999; Etkin et al. 2006; Kemp and Manahan-Vaughan 2004, 2007, 2008a; Goh and Manahan-Vaughan 2012).

The precise contributions of LTP and LTD to spatial representation are tightly linked to the respective hippocampal subregions (Kemp and Manahan-Vaughan 2008a; Hagena and Manahan- Vaghan 2011). What is striking, however, is that D1/D5 receptors regulate both persistent LTP (Huang and Kandel 1995; Lemon and Manahan-Vaughan 2006) and persistent LTD (Lemon and Manahan-Vaughan 2006), suggesting that these receptors exert control over the kind of information contributed by the different forms of synaptic plasticity to memory representations.

Effect of D_1/D_5 Receptor Activity on Hippocampal LTD

LTD to some extent is a mirror image of LTP, comprising persistent decreases in synaptic strength that occur following patterned afferent stimulation to the hippocampus. In recent years, it has become apparent that this phenomenon is an information storage mechanism that likely cooperates with LTP to generate spatial and/or memory representations (Kemp and Manahan-Vaughan 2007).

D_1/D_5 Receptors and Learning-Facilitated Plasticity Novel spatial exploration concomitant with afferent stimulation combined with D_1/D_5 receptor activation also enables a slow-onset depression in CA1 synapses, thereby also supporting that D_1/D_5 receptor activation might lower the threshold for information storage by LTD in hippocampal synapses (Lemon and Manahan-Vaughan 2011; Table 1B). Thus, learning-facilitated E- and L-LTP can be modulated by activating D_1/D_5 receptors (Table 1A). Again, this finding links the D_1/D_5 receptors strongly to novel experience and suggest that these receptors may be one of the factors that confer salience and relevance to incoming sensory information reaching the hippocampus.

Effect of D_1/D_5 Receptor Activity on Hippocampus-Dependent Learning the aforementioned findings suggest that a very tight link exists between the regulation of synaptic plasticity by D1/D5 receptors and their role in hippocampus-dependent learning.

The hippocampus plays a crucial role in learning and memory (Eichenbaum et al. 1990; Mishkin et al. 1998) and is involved in spatial and episodic memory (Burgess et al. 2002). The dopaminergic midbrain participates in human episodic memory formation (Schott et al. 2006). Furthermore, in rodents, long-term memory of hippocampus-mediated acquisition of new paired associates (episodic-like memory task) requires the activation of D_1/D_5 receptors. In contrast, early memory is unaffected by D_1/D_5 receptor antagonism (Bethus et al. 2010), and [DA] has no effect on already-established memories or on retrieval (O'Caroll et al. 2006).

D_1 agonist treatment in rats enhances hippocampus dependent spatial memory (Bach et al. 1999; da Silva et al. 2012) without affecting nonspatial memory (da Silva et al. 2012). By contrast, D_1/D_5 receptor antagonists impair short and long-term spatial memory (Clausen et al. 2011; da Silva et al. 2012). Studies in transgenic mice suggest that the D1 receptor (El-Gundi et al. 1999) and not the D_3 or D_5 receptor are essential for spatial learning (Granado et al. 2008; Xing et al. 2010). The D_1 receptor is also crucial for the encoding of novel environments and hippocampal representations of plasticity (Tran et al. 2008).

The D_1 receptor is critical for the induction of Zif268 and arc, proteins required for the transition of E-LTP into L-LTP and memory consolidation in mammals (Granado et al. 2008), and the activation of D_1/D_5 receptors is required during memory encoding to generate a persistent memory trace in the hippocampus (O'Carroll et al. 2006). Learning-dependent changes in synaptic strength of other forms of hippocampal-dependent learning, such as classic 'eye blink' conditioning (Kuo et al. 2006, Suzuki 2007; Madronal et al. 2009), are also modulated by D_1 receptor activation (Ortiz et al. 2010).

These findings suggest that D_1/D_5 receptor activation is a crucial factor in the formation of spatial long-term memory in the mammalian brain. D_1/D_5 Receptors are Pivotal for Hippocampal Information Storage Based on current knowledge, it is clear that D_1/D_5 receptors play an intriguing and decisive role in the enablement of information encoding and storage in the hippocampus.

They can facilitate the expression of both LTP and LTD, and taking into account the accumulating evidence that LTP encodes different aspects of spatial representations (Kemp and Manahan-Vaughan 2007, 2008a; Goh and Manahan-Vaughan 2012), this suggests that D_1/D_5 receptors can drive the nature and qualitative content of stored information in the hippocampus. Strikingly, on a functional level and in line with this postulate, D_1/D_5 receptor activation leads to increased processing within the trisynaptic DG–CA3–CA1 circuit, to the disadvantage of the direct entorhinal–CA1 input (Varela et al. 2009), thereby minimizing the influence of mismatch detection (Lismann and Otmakhova 2001) in favour of prioritizing information storage.

This in turn is likely to be highly relevant in the coupling of information storage and memory with reward experiences. Taken together with the observations that D1/D5 receptor activation modulates hippocampus-dependent episodic and spatial long-term memory, these data indicate that D1/D5 receptors gate hippocampal long-term plasticity and memory in the mammalian brain, and are pivotal in conferring the properties of novelty and reward to information being processed by the hippocampus.

MICE LACKING D_5 DOPAMINE RECEPTORS HAVE INCREASED SYMPATHETIC TONE AND ARE HYPERTENSIVE

Hollon et al

2002

Molecular Neuropharmacology Section and Basic Neurosciences Program, National Institute of Neurological Disorders

Dopamine is an important transmitter in the CNS and PNS, critically regulating numerous neuropsychiatric and physiological functions. These actions of dopamine are mediated by five distinct receptor subtypes. Of these receptors, probably the least understood in terms of physiological functions is the D5 receptor subtype. To better understand the role of the D5 dopamine receptor (DAR) in normal physiology and behaviour, they have now used gene-targeting technology to create mice that lack this receptor subtype.

They found that the D_5 receptor deficient mice are viable and fertile and appear to develop normally. These results indicate that D_5 dopamine receptors modulate neuronal pathways regulating blood pressure responses and may provide new insights into mechanisms for some forms of essential hypertension in humans, a disease that afflicts up to 25% of the aged adult population in industrialized societies. Interestingly, recent reports have suggested a possible association of the D_5 DAR gene with schizophrenia (Muir et al., 2001) or substance abuse (Vanyukov et al., 1998).

D_5 DARs are also expressed in the hypothalamus, where they may regulate circadian rhythms (Rivkees and Lachowicz, 1997) and female sexual behaviours (Apostolakis et al., 1996a,b). Within the periphery, D_5 DARs have been found in adrenal tissue (Dahmer and Senogles, 1996), kidney (Sanada et al., 2000), and also the gastrointestinal tract, where they may exert a protective effect on the intestinal mucosa (Mezey et al., 1996). To further elucidate the physiological roles of the D_5 DAR, they have now used gene targeting technology to generate mice lacking functional D_5 DARs.

Dopamine receptors, including the D_5 DAR, are present in the prefrontal cortex (Ariano et al., 1997; Ciliax et al., 2000), which projects to several brain areas involved with cardiovascular regulation (Verbene and Owens, 1998). Sympathetic responses from the prefrontal cortex are mediated within the lateral hypothalamic area (LHA) and ventrolateral medulla (VLM). Moreover, sympathetic responses originating in the prefrontal cortex and LHA are mediated by non-NMDA glutamate receptors in the VLM (Butcher and Cechetto, 1998). Indeed, CNS stimulation of non-NMDA glutamate receptors, specifically in the VLM, increases blood pressure (Chen et al., 1994; Araujo et al., 1999).

Their studies suggest that the increased blood pressure in the D_5 DAR-deficient mice may be caused by activation of a sympathetic/non-NMDA glutamatergic axis because only a centrally acting non-NMDA glutamatergic antagonist decreased blood pressure in D_5 mutant mice.

The D_5 receptor may also negatively interact with oxytocin and vasopressin pathways in the prefrontal cortex and other brain areas associated with autonomic control (Ariano et al., 1997; Hermes et al., 1998; Buijs and Van Eden, 2000; Ciliax et al. 2000). Thus, V1 vasopressin (Bealer and Abell, 1995) and oxytocin (Boccia et al., 1998) antagonists that cross the blood–brain barrier were found to decrease the blood pressure in the D_5 mutant but not wild-type mice.

In summary, they found that functional deletion of the D_5 DAR gene produces hypertension in mice. ***The elevated blood pressure appears to be attributable to increased sympathetic tone with an involvement of adrenal catecholamines***. The exact defect leading to the increase in sympathetic tone is unclear, although it appears to be primarily central in origin.

Their current results suggest that D_5 receptor deletion results in an oxytocin dependent sensitization of V1 vasopressin and non-NMDA glutamatergic receptor-mediated pathways, potentially within the medulla, leading to increased sympathetic outflow in the mutant mice. This change is not associated with increased synthesis of either oxytocin or vasopressin, and in fact, vasopressin synthesis appears reduced in the D_5 DAR-deficient mice.

Furthermore, there is no increase in oxytocin or V1 vasopressin receptor numbers. This suggests that the increased sensitivity must occur at the level of receptor signalling, possibly via enhanced G-protein interactions, or other regulatory mechanisms, and/or downstream intracellular signalling pathways.

The physiological events described here resulting from D_5 DAR deletion may provide new insights into mechanisms for some forms of essential hypertension in humans and may lead to new therapeutic approaches for its treatment.

The above scientific clinical data sets offer a clear emergent and defining link, between neurological interactions that highlight environmental surroundings that affect the individual’s perception. This striatal synaptic plasticity suggests that were Bastian placed in an environment unsuitable to his own self-awareness and perception, it could induce tachycardia. Tachycardic episodes have happened on more than one occasion as a direct result of adrenal passing through the neurological pathway, which causes increasing D_5, thus impacting on a sudden and dangerous levels hypertension.

DISTINCT ROLES OF D_1 AND D_5 DOPAMINE RECEPTORS IN MOTOR ACTIVITY AND STRIATAL SYNAPTIC PLASTICITY

Centonze, et al.

2003

Stimulation of dopamine [DA] receptors in the striatum is essential for voluntary motor activity and for the generation of plasticity at corticostriatal synapses. Understanding the role of [DA] receptors in striatal function is essential to gain insights into the neural bases of critical brain functions and of dramatic pathological conditions such as Parkinson’s disease, schizophrenia, and drug addiction. Dopamine [DA] signalling in the striatum plays a central role in a variety of motor and cognitive activities. Abnormal striatal [DA] transmission is involved in several neuropsychiatric diseases, such as Parkinsonism, schizophrenia, and drug addiction (Berke and Hyman, 2000; Lewis and Lieberman, 2000; Obeso et al., 2000).

Endogenous [DA], released from midbrain [DA] neurons, modulates striatal function by interacting with [DA] receptors. Among the various subtypes of [DA] receptors, to explain the dual role of D_1 receptors in motor control, it can be speculated that D_1 receptors synergize with D_5 receptors when the two receptors are activated in the same cellular subtype, but they oppose to each other when activated in distinct neuronal populations.

This hypothesis is supported by the following data. First, both D_1 and D_5 receptors are positive regulators of cAMP levels (Grandy et al., 1991; Sunahara et al., 1991; Tiberi et al., 1991; Vallone et al., 2000) and therefore cooperate in triggering common cellular events when coexpressed. In this respect, D_5 receptors are also expressed in medium spiny neurons of the striatum (Rivera et al., 2002a; present study), a neuronal subtype particularly enriched in D_1 receptors (Gerfen et al., 1990; Le Moine et al., 1991; Surmeier et al., 1992, 1996; Aizman et al., 2000).

Second, D_1 and D_5 receptors are primarily expressed in different striatal cell populations (Bergson et al., 1995; Surmeier et al., 1996; Yan and Surmeier, 1997; Rivera et al., 2002a), suggesting that they can also exert distinct physiological actions. Noticeably, NOS-positive neurons, which express D_5 receptors and are stimulated by D_1 - like receptor agonists, do not have D_1 receptors (Le Moine et al., 1991; Kawaguchi et al., 1995; Rivera et al., 2002) and cause longterm inhibition of the excitability of striatal spiny neurons, thereby contrasting the direct LTP-favoring effects of D_1 receptors on these cells.

The use of the recently generated mice lacking D_5 receptors (Holmes et al., 2001; Hollon et al., 2002) could help to clarify this important issue. Complex regulatory role of [DA] receptors in corticostriatal synaptic plasticity Repetitive stimulation of corticostriatal pathway can induce either LTD or LTP both *in vivo* (Charpier and Deniau, 1997; Reynolds and Wickens, 2000) and *in vitro* (Calabresi et al., 1992; Dos Santos Villar and Walsh, 1999; Partridge et al., 2000).

Persistent changes in synaptic strength in the striatum are considered as neural correlates of specific motor abilities, although more recently have been involved in several other aspects of brain activity, such as reward-related learning (Berke and Hyman, 2000; Reynolds et al., 2001), maturation of neural circuitry during development (Choi and Lovinger, 1997), and drug addiction (Berke and Hyman, 2000; Hyman and Malenka, 2001; Nestler, 2001).

Striatum is an important component of motor, cognitive, and limbic circuits. This nucleus takes part in several brain activities by processing the flow of information arising from different neocortical areas and projecting to the thalamus (Bergman et al., 1998). [DA] plays a crucial role in these processes by affecting the activity of striatal cells through multiple mechanisms.

Interestingly, a complex interplay between different subtypes of [DA] receptors is required for both striatal motor control and synaptic plasticity, possibly involving different subpopulations of striatal neurons.

Investigating the receptor and cellular mechanisms involved in striatal motor control and synaptic plasticity is an essential requirement to understand the neural bases of *critical brain functions* and of dramatic pathological conditions, such as Parkinson’s disease, schizophrenia, and drug addiction.

IMPLICATIONS OF NEUROBIOLOGY OF EMOTION FOR EDUCATION

Phillips

2003

“If a child can't learn the way we teach, maybe we should teach the way they learn.” (Ignacio Estrada)

To understand emotion in educational environments we have to address the brain/neurological process and growth for development thereof.

- Teacher – Child – Peer Interactions
- Holistic Education
- Strengthening of Neurobiology
- Development of Awareness
- Attending to Emotion

Teacher – Child – Peer Interactions

The nature and quality of teacher-child peer to peer social and academic interaction impacts brain development, attention and learning, therefore the environmental setting would be the key factor in establishing a focus and positive outcome.

Holistic Education

Education can be considered to be a critical influence in strengthening the neocortical control and self-awareness.

Strengthening of Neurobiology

Strengthening of frontal lobe capacities, and the management of both positive and negative emotions based on attainting and understanding a personal individual based curricular are critical to academic, social and person outcomes.

Development of Awareness

Helping children develop awareness process via frontal lobe functions of interpersonal awareness and self-control.

Attending to Emotion

Attending patiently to children’s emotions and their efforts as a central part of class room processes will lead to improved personal and academic outcomes based on his or her individual abilities.

MODEL OF EMOTIONAL INTELLIGENCE **Salovey & Sluyter (1997)**					
EMOTIONAL INTELLIGENCE		**Reflective regulation of emotions to promote and intellectual growth**			
		Level 1:	Level 2:	Level 3:	Level 4:
		Ability to stay open to feelings, both those that are pleasant and those that are unpleasant	Ability to reflectively engage or detach from an emotion depending upon its judge informativeness or utility	Ability to reflectively monitor oneself and others, such as recognizing how clear, typical, influential and reasonable they are	Ability to manage emotion in oneself and other by moderating negative emotions and enhancing pleasant ones, without repressing or exaggerating information they may convey
		Understanding and analysing emotions: Employing emotional knowledge			
		Level 1:	Level 2:	Level 3:	Level 4:
		Ability to label emotions and recognize relations among the words and the emotions themselves, such as the relation between liking and loving	Ability to interpret the meanings that emotions convey regarding relationships, such as that sadness often accompanies a loss	Ability to understand complex feelings – simultaneous feelings of love and hate, or blends such as awe as a combination of fear and surprise	Ability to recognise likely transitions among emotions, such as the transition from anger to satisfaction, or from anger to shame
		Emotional facilitation of thinking			
		Level 1:	Level 2	Level 3	Level 4:
		Emotions prioritise thinking by directing attention to important information	Emotions are sufficiently vivid and available that they can e generated as aids to judgement and memory concerning feelings	Emotional mood swings change the individual's perspective from optimistic to pessimistic, encouraging consideration of multiple points of view	Emotional states differentially encourages specific problem approaches, such as when happiness facilitates inductive reasoning and creativity
		Perception, appraisal and expression of emotion			
		Level 1:	Level 2:	Level 3:	Level 4:
		Ability to identify emotion in one's physical states, feelings and thoughts	Ability to identify emotions in other people, designs, artwork etc. through language, sound, appearance and behaviour	Ability to express emotions accurately and to express needs related to those feelings	Ability to discriminate between accurate and inaccurate, or honest versus dishonest expressions of feeling

Table 2: Model of Emotional Intelligence. Salovey & Sluyter (1997)

CHOOSING A SCHOOL FOR A CHILD WITH SPECIAL NEEDS

Birnbaum

2010

“The word ***child*** applies to anyone under the age of 19 years. When the UK government initiative on Every Child Matters (ECM) was launched in 2003, which led to the Children Act 2004, the word child was applied to anyone under the age of 19 years.

The term learning difficulties and / or disability refer to children who have either a learning difficulty in acquiring new skills or who learn at a different rate to their peers. Research suggests that approximately 2 per cent of the population may have learning difficulties. This terminology transcends professional boundaries between education, health and social services so that the same language is used to explain the needs of children 0-19 years. The disability Discrimination Act 1995 Section 1 (1) defines that:

> A person has a disability for the purposes of this Act if he has a physical or mental impairment that has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

Physical or mental impairments can include sensory impairments and learning difficulties. This definition also covers medical conditions where there is long-term and significant impact on children’s everyday lives. Those children designated with special education needs (SEND) under the current education legislation, all have learning difficulties and or disabilities that make it harder for them to learn compared to most learners of the same age.

No one is ever prepared when having a special needs child, developmental difficulties know no boundaries. Parents, in particular, have to learn that after coming to terms with the initial shock they must also grapple with the machinations of Government, Local Authorities, Children’s Services, social services and in some cases Legal Services.”

Bastian and his mother have not only grappled with all of the above services but have been subjected to unlawful and illegal due processes, whilst arduously accessing and securing provision for Bastian’s SEND based ratified UK legislation.

Learning Difficulty

Learning difficulties are identified into three categories within the UK

Range of Difficulties		
IQ	Category	Educational Team
50-70	Moderate / Mild learning Difficulty	Moderate Learning difficulty (MLD) *****
20-49	Severe learning disability	Severe learning difficulty (SLD) *****
Less than 20	Profound learning disability	Profound and multiple learning difficulty (PMLD)

Table 3: Table IQ Range UK

***** Some children with an uneven profile, whose overall IQ falls in the SLD category may be described as having MLD if some of the scores are higher or vice versa. ** This applies directly to Bastian. Bastian's IQ is set at a measured profile of 49-50.

Moderate Learning Difficulty

Children with moderate learning difficulties (MLD) also sometimes descried as 'global learning difficulties', have a general development delay. They have difficulties across all areas; namely:

- Have difficulties with comprehension
- Need a high level of support with problem –solving activities or generate thinking
- Have poor verbal and non-verbal reasoning skills
- Have immature listening / attention skills which will affect their concentration
- Have immature social skills
- Have difficulties applying what they know to new or novel situations
- Usually have poor auditory and visual memory
- Have difficulty acquiring basic literacy and numeracy skills
- Have some motor co-ordination difficulties which will affect written skills
- Rely on teaching assistants, teachers or peers to direct the within the class room environment.

Children with moderate learning difficulties may also suffer from low self-esteem and lack of motivation. In view of their failure at school, they may become resentful, refuse to attempt new work or perceive themselves as a failure even before a task begins. Children with MLD usually require praise and encouragement to persuade them to adopt strategies and to develop greater independence both in their learning and general life skills.

Severe Learning Difficulty

Children with severe learning difficulties (SLD) have a significant cognitive delay which has a major effect on their ability to access the school curriculum without support. Children with SLD are likely to have problems with mobility and motor co-ordination, speech, language and communication and a delay in their self-help and independent skills.

Children with SLD will need support I all areas of the curriculum. For much of their schooling, attainment will be in the upper P Scale range (P4-P8) of the National Curriculum and IQ's will generally measure between 20 to 49, but STATS testing are often inappropriate for these children and functional, developmental or dynamic assessments are preferred methods of assessment.

There are some children with SLD in mainstream schools; however the SENCo will consider with parents the appropriateness of a mainstream place with regard to the take up. There are inclusion strategies and even written UK legislation to support his, if such a place is wanted and can be provided.

Profound and Multiple Learning Difficulties

Children with profound and multiple learning difficulties (PMLD) require a high degree of supervision in their daily life because they are functioning at very early levels of development. Such children may have little or no spoken language, may be barely ambulant or non-ambulant and have difficulties in manipulating objects, they may be unable to feed, dress or toilet themselves independently. Most of these children will also have additional difficulties in physical, auditory or visual areas, including the function use of these abilities.

Most of these children are operating at the very early stages of the P Scales, usually between P1 and P4. These children will usually be in special school, which have developed multi-sensory environments. However, with the advent of IT (information technology), emphasis is gradually moving from sensory environments and relaxation to new pedagogic approaches, such as switch technology which allows children to interact, be stimulated and to feedback their responses to adults, enabling them to exercise a degree of control over their environments and experiences.

[The research by Birnbaum above sets out the distinctive groupings of Special Needs, however the complexity of Bastian is just that, complex; Bastian covers all of the identifiers based on the UK IQ range table. Defining Bastian as an enigma; profound, severe, moderate, including being highly intelligent – therefore a 'Contradiction in Terms'; fitting neither mainstream or special educational profiling.]

Birnbaum sets out her research on Behaviour, Emotional and Social Development as (BESD)

Behaviour, Emotional and Social Development

Children should be recorded as having (BESD) if it is their primary or secondary special education need and they are at School Action Plus or have a Statement* now known as EHCP (Educational Health Care Plan – 2014).

BESD covers the full range of ability and encompasses a number of diagnostic categories' both complex needs and conduct disorders. The category of BESD is probably the most relative and interactional of all the special education needs categories identified. ***The Severity may be difficult to define based on different environments and with respect to individuals. In most situations, the behaviour is a result of stress perceived by the child***. The child will often exhibit a fight or flight response, either becoming fearful, withdrawn or exhibiting aggressive, antisocial and disruptive behaviours.

Children are usually identified with having BESD if their behaviour:

- Is not age appropriate
- Results in isolation from peers
- Negatively affects the class room or learning environment
- Places unreasonable demands on teaching staff
- Leads to negative self-concept and low self-esteem
- Restricts learning opportunities (both for the child concerned and others in the class/school)
- Creates dangerous situations

The above points identify the exacting markers which Mark Carter highlights in his report (NHS CAHMS, May 2014) in which Bastian could end up on both sides of the scale, acting out or regressing; therefore undoing all the previous therapeutic inputs, were he to be placed in an environment which does not support his owl self-awareness and perceptions.

Many strategies have been applied and tried to eliminate and or reduce BESD however some behaviours have inadvertently increased stress, and in some cases the *environment* itself has been the cause. Sometimes it is the interaction between the child and the environment that is the problem. A change of teaching arrangement and or environment/schooling strategies may be necessary to avoid undue or unnecessary BESD.

The concept of ‘emotional intelligence’ is now frequently seen in psychological reports and there are now some standardised tests that yield an emotional intelligence (EQ) score. Emotional intelligence is a person's ability to manage in the following domains:

1. Knowing one’s emotions – self-awareness and recognising a feeling as it happens (this is a keystone to EQ)
2. Managing emotions and handling feelings
3. Recognizing oneself and emotional self-control
4. Recognising relationships social competence and incompetence which include specific skills involved which will underpin popularity leadership, leadership, and interpersonal effectiveness; all necessary qualities for interacting with groups in school.

Emotional Intelligence will have a profound intelligence on both children and teachers who are managing classrooms. Emotional literacy which is the ability to identify and communicate feelings is the starting point for many of the interventions for children with BESD. These approaches have their roots in therapeutic interventions which often provide the necessary supportive framework within schools.

Complex Needs

Complex needs (sometimes used interchangeably with the description of multiple needs) usually defines a group of children with multiple needs (more than one) that are inter-related. Needs may vary from profound to moderate, but the defining feature is that the end presentation will transcend several different areas of need, providing quite a challenge to an educator. Children with complex needs will have to negotiate a number of different issues in their life, and each child will have a unique interaction of strengths and weaknesses, requiring a personalised and individualised response from different educational, therapeutic and social services. Thus, in addition to looking at the complexity of special educational needs, children who fall into this category of having complex needs are those who span different departments in a Local Authority because of their social and emotional needs.

The Common Assessment Framework (CAF) which was introduced as part of Every Child Matters (ECM) Programme was intended to co-ordinate early assessments of children with less significant needs who would benefit from short-term targeted intervention in a preventative fashion, but whose difficulties would fall short of thresholds of specialist services.

[It is the researches hypothesis that the CAF was introduced and policed as a means of a short term resolution to aid the ECM Framework without a thorough in-depth analysis taking into account the needs of complex children.]

Birnbaum goes on to state: ‘Children with complex special educational needs, frequently with their health needs arising from clinical diagnoses, are still falling through the net because of the lack of integrated services, although some Local Authorities are moving towards the development of integrated assessment frameworks to address this problem.’

There are a number of genetic syndromes that will come under the heading of *Complex Needs*, one of which is *SETD*$_5$, as discussed in this report; however what legislators and or policy drafters don’t consider is that genetic syndromes can often be rare or rare with complexities. Although there is Legislation and legislative guidance, supporting rare diseases; ‘Rare Disease Strategy UK, Department of Health, November 2013’ Local Authorities fail to apply this legislation and use its guidance when assessing special educations needs provision.

The researcher pooled a sample of 36 (parents), whose children all have variant complex Special Educational Needs and posed the following question:

> “Has the CAF been of use and or beneficial to you and or your child/family?”

The general consensus is as follows:

The CAF is only beneficial when the lead is competent in handling the complexity of SEND provision and only beneficial when critical support is offered, so as to back up said CAF and for what it was intended. The CAF has done more damage by adding yet another layer of due process and for very little in return, of no real benefit. It adds complexity to an already difficult process seeking adequate SEND provisions; however, there was an outlier within the sample group – the detailed that the CAF did highlight that various provisions were not being met and that the various schooling placements was indeed incorrect or ineffective.

Physical School Environment in General

Children’s learning can be greatly influenced by their surroundings. The layout and environment all have a significant and major impact, particularly on children with SEND. There are behavioural issues which might also be created by environmental conditions.

Children with BESD will often instinctively know if a school environment is in alight with the self-awareness. Environmental issues have been recognised as being quite critical and, indeed a school which went into special measures was recently heralded by a multi-disciplinary team of psychologists, researchers, educational psychologists and managers as having had a significant impact on the pupil attainment, achievements, culture change and teaching staff.

A vital question in researching a placement for a SEND Child, is:

- For children with emotional and behavioural difficulties, is the environment calm and secure?

Parental Involvement

The Special Education Needs Code of Practice includes a chapter entitled ‘Working in Partnership with Parents’. Whilst one would always hope that relationships between parents and school will be smooth and mutually beneficial, given the kinds of issues that may arise, both parties will need a lot of understanding and benefit of the doubt. The Code of Practice states: All parents of children with SEND should be treated as ‘partners’’ (para.2:2). Parents should be supported and empowered to:

- Recognise and fulfil their responsibility as parents and play an active and valued role in their children’s education
- Have knowledge of their child’s entitlement with the SEND framework
- Make their ***rights and views*** known including how their child is educated
- Have access to information, advice and support during assessment and any related decision-making processes about special educations provision.

Professionals visiting schools will also want to ensure parental voices are heard.

It is with great regret that no such opportunities were offered to both Bastian and his mother, as the Local Authority in question failed to respond to the primary school’s Head Teacher, the Primary School’s Deputy Head and SENDCo, communications, including Bastian’s mother’s communications’, which saw The London Borough of Barnet failing to attend a vital and critical professionals meeting which included the legal annual transitioning reviewing of Bastian transitioning to a Unique Special Secondary school.

Transition

Parents and Professionals need to consult the Local Authority so as to implement a smooth transition, especially from primary to secondary which is extremely stressful for any child let alone a child with complex SEN. The Local Authority in question did not adhere to its own policy and thus Bastian’s Primary School SENCo, Mother and School Community Nurse together with his Analytical Psychoanalyst had to prepare Bastian for the transition that did not take place. The preparations included undertaking an 18-month research period which sought out 35 schools to determine an appropriate school for secondary school transition based on Bastian’s complex needs.

GIFTED & TALENTED CHILDREN WITH SPECIAL EDUCATIONAL NEEDS
Double Exceptionality

Diane Montgomery

2003

A Neurodevelopmental Approach to Learning Disabilities: Diagnosis and Treatment

Shirley Kokot

Many gifted children are recognised as having neurobiological problems that interfere with academic and social / emotional functioning. It is common practice to label these according to symptoms they manifest. Labesl frequently used are e.g. Perceptual Problems, Dyslexia (Winner 2000) or Dyspraxia (Neihart 2000) and so on. These conditions may be accompanied by Learning Disabilities [LD] that persist in spite of diverse therapies being tried by often desperate parents.

Therapeutic approaches to learning disabilities

Many different therapies exist that claim to successfully treat particular learning disabilities. Most gifted children with learning disabilities show a scatter of high and low abilities across different tasks. Early theorists and specialists in the field of learning disabilities believed that composites of traits or faculties (called 'processes') were activated when a child performed a task. Weakness in one or more of the processes would account for the child's failure on the task. Following this, it seemed logical that strengthening the faulty process would lead to improvement of the child's performance (Farnham-Diggory 1992).

Among these specialists were Ayres, who focused on sensory integration; Kehphart, on perceptuomotor matching; Frostig, on visual-perceptual training, Delcanto, on neurological organisation, and many developmental optometrists, who believed that aberrant visual systems have an impact on reading and subsequent learning. However, during the 1970's and 1980's these theories and related practices were evaluated and found to be scientifically invalid and ineffectual.

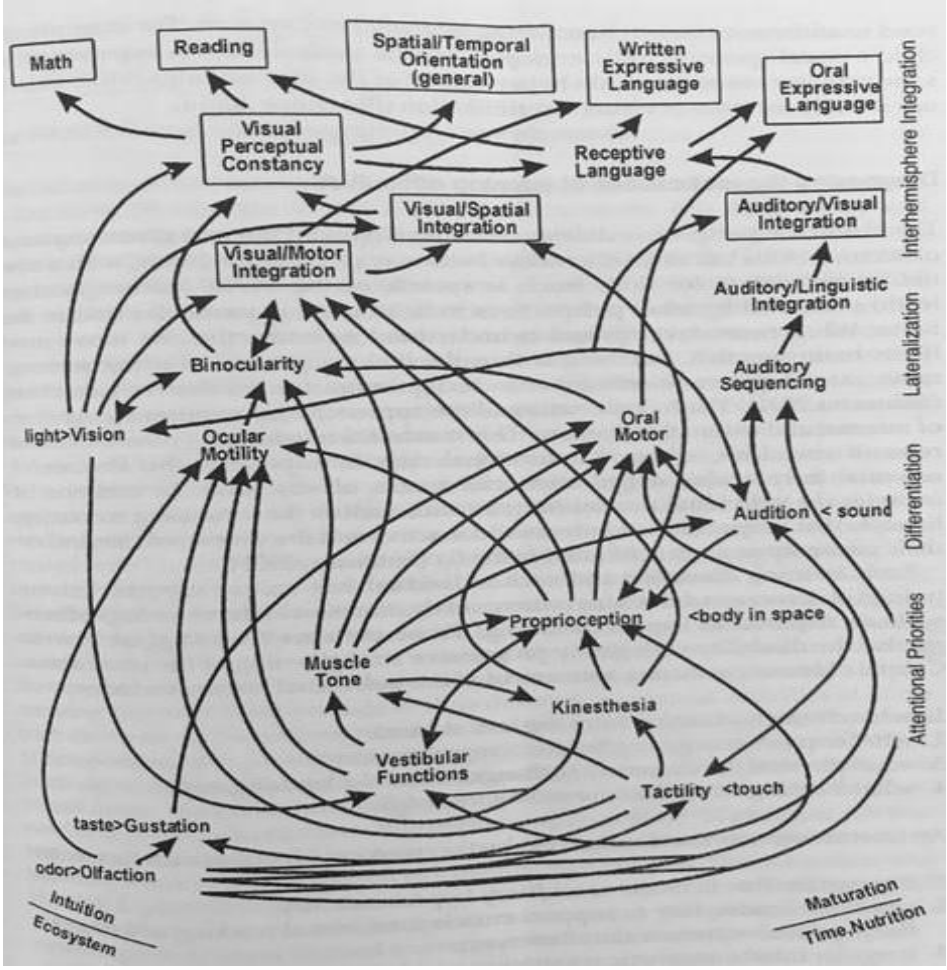
The late 1980's and 1990's saw an explosion of brain research that clarified some issues and, indeed, led to support for the basis of many of the earlier theories. It seems to be accepted now that movement is responsible for the structure of the brain (Changeux and Conic 1987; Ito 1984; Lisberger 1988) and that the brain's proven plasticity means that through movement, it becomes possible to restructure the brain. (Le Poncin, 1990). These findings mean, in effect, that the body organises the brain rather than the other way round.

[The researcher thus hypotheses' that when a learning disabled [LD] child is placed in an adverse schooling environment the physical manifestation and onset of stress will ultimately affect the child's cognition, therefore causing regression within the plasticising brain, altering the brains functionality and structure.]

Kokot goes on to state, Given this understanding of how the brain functions, it is likely that individuals struggling to cope with the demands of life and learning may be doing so not because of brain damage in a specific areas of the brain, but rather due to inefficient functioning of several interactive sensory and motor sub-systems. (Lewis 2001) found that some individuals need more energy to function, and Bluestone arrived at a new treatment for learning difficulties called the HANDLE approach, 'Holistic Approach to Neuro Development and Learning Efficiency. (HANDLE).

A hierarchy of integrated systems

Bluestone developed a chart that represents the diagrammatically integrated and interdependent sub-systems responsible for our efficient functioning. The relative position of each sub-system on the chart is indicative of the hierarchical nature of the neurological system and illustrates how higher-level functions depend on those at a lower level. For example, problems with reading or maths may be traced all the way back to a dysfunctional vestibular system. In this way, HANDLE attempts to identify the roots of a learning problem. Practitioners drafting a therapy plan would sequence and prioritise exercise activities according to where an individual's weaknesses would show up on the hierarchy.



Graphic 1: Chart Showing Bluestone's representation of integrated and independent sub-systems – (Montgomery, 2003)

Lowest level systems would be addressed first so that, strengthened, they may support the functions of higher-level systems which could then benefit optimally from corrective therapeutic activities. Whilst such an approach may possibly improve a particular splinter skill at the time, it would not resolve the causal issue. This results in the weakness remaining to affect other skills – possibly simultaneous in time, such as interpersonal and emotional skills, but assuredly, skills that show up later – needing those same weak foundations.

In addition, even if the higher-level function is relatively intact, energies from these higher levels may be used to compensate for a weakness in a more foundational system, emphasising to need to address inefficient functioning of lower level systems. For example, if a child's visual system is well developed, but the tactile system is hypersensitive he/she may use vision to remain hyper vigilant of the surroundings rather than to use it freely for task of visual discrimination. (Bluestone 2001)

Diagnosing the root causes of learning difficulties

The HANDLE perspective defines neurodevelopment not as a given sequence of accrued skills but as an interactive hierarchy of brain functions, with a vestibular foundation for skills (such as speech, math, visual tracking and so forth) presumed by other perspectives to be isolated in particular sites in the brain.

When neurodevelopment is understood as interactive, no time frame limits brain function. Learning is thus the lifelong process of using sensory, motor, social and emotional input to realign output into effective behaviour (Suliteanu, 2001).

The holistic nature of the approach also requires recognition of internal influences. This means acknowledging possible causal roles of chemicals, allergens, nutritional deficits (especially the absence of essential fatty acids), dehydration and toxins of any kind. It addition, it includes the individual's social environment, such as the increasing cocooning lifestyle that keeps children indoors and inactive, and the decreased demand on their creativity as a result of graphic media (Suliteanu, 2001).

Each learning disability and each individual has unique aspects, but the trained observer can determine patters of dysfunction in the neurological subsystems required to support learning. (*These observers are often the Parents who are intrinsically linked to their children by every day continued minuscule mannerisms that are often undetected by even the most trained professionals' eye*).

Those patterns then suggest how to resolve the disability with gently progressive strengthening of the weak areas. Crucial observation during assessment of the individual learner includes:

- What distracts attention from the tasks at hand
- What requires energy needed for comprehension
- What physical/environmental changes affect the learning
- What learning modalities are the most successful?

An interactive, non-standardised evaluation protocol identifies such factors as:

1. Distractions due to tactile or auditory hypersensitivity
2. Vestibular inadequacy to support muscle tone, visual tracking and linguistic / phonetic awareness simultaneously
3. Irregular interhemispheric integration interfering with auditory-visual integration, parts-to-whole configuration as well as problems with central auditory processing due to an inability to integrate the word / language component with the picture / meaning of the word

4. Light sensitivity and visual-motor dysfunctions that cause irregular visual / visual-motor feedback, etc.

Once information concerning the important issues has been gleaned from the individual's behaviour during assessment, an appropriate programme composed of activities and exercises is designed to strengthen the weak functions and resolve learning at their roots.

The HANDLE treatment programme – Key Elements

The hierarchical and interactive nature of the neurodevelopmental sub-systems is crucial to the success of this approach. To reiterate, it is futile to try and improve the efficiency of higher-level systems before systems at a lower level are regulated and integrated. Lower level systems include the senses of touch, taste, and smell as well as the vestibular ad proprioception systems. The visual and auditory systems are at a higher level, and at the highest-level would-be systems relying on integrated interhemispheric functions, such as visual-spatial, auditory-linguistic processes, and so forth.

[The researcher suggests that, as Bastian is already emotionally intelligent and his higher level sub-system is stable, placing him in a suitable schooling environment by his own self-acknowledging perceptions would be critical in keeping that higher level sub-system stable and intact, so as to keep the hierarchical and interactive nature regulated. As Bastian's vestibular and proprioception systems are already clinically diagnosed as damaged or unstable, it would therefore make practical sense to keep Bastian within the HANDLE parameters of the key elements.]

GIFTED WITH BEHAVIOUR DISORDERS

Marching to a different drummer

Dorothy Sisk

Sociocultural

“If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far way.” Henry David Thoreau

Individual differences have intrigued and challenged educators for centuries and the understanding and application of this concept greatly motivates educators; yet, practical classroom responses to individual differences are elusive, particularly for gifted and talented students.

One pioneer in gifted education in the United States, Ruth Martinson, said individual differences are positive and should be considered as a resource in school. She stressed that effective schooling expands the differences between students, rather than restricting them. Martinson championed the idea of expanding diversity, rather than seeking conformity and inappropriate uniformity.

The researcher (Normal-Like-Me) has spoken with CAMHS (Child and Adolescent Mental health Service, NHS-England) and was offered an off the record statement:

“All disabled children are seen as the same, and therefore all placed into the same schooling environment regardless of their cognition, rarity, ability or disability. We at CAHMS struggle month to month, year on year with this concept; our years’ worth of reporting and in-depth analysis of children with SEND are dismissed, however our hands are tied, as the purse strings are held by Local Authorities/CCG (Clinical Commission Groups) and our recommendations are very rarely taken on board by LA Officers including Educational Tribunal Judges via The SENDIST Legal Framework. The LA Officers, including those who preside over the law, have never met the children in question nor have they ever spent considerable amounts of time underpinning their specific needs.

There are many children wrongly placed in unsuitable and adverse schooling environments, and the effect on the child/family is often regression and or a direct pathway into a long-term Adult Mental Health Institution, this is and does have a significant knock on effect on all public services. Thus, the initial placement that may have cost an extra sum of money will end up costing public services ten times the amount to ‘repair’ the significant neurological and psychological damages across the board.

This is known as counterproductive psychology by leading psychoanalysts. The known ‘phrase’ or legislation caveat that is used by UK by Local Authorities is legislated as: ‘Best use of public resource.’

It is the researcher’s hypothesis that the ‘cost benefit model’ in relation to the “Best use of public resource” is wholly skewed and disproportionate when using this legislative caveat, which can be seen as unlawful when assessing and placing SEND children into adverse schools or adverse environments.

The researcher recommends an in-depth Public Health study to be carried out on the cost benefit model so as to arrive at the true ‘cost/expenditure’ when children of SEND are placed at or schooled inadequately with regards to their individual needs (0-25 years). It is this ‘true overall cost’ that ultimately affects best use of public resources.

> *"An ounce of prevention is worth a pound of cure. It's more prudent to head off a disaster beforehand than to deal with it after it occurs.” – 'De Legibus' (c. 1240) by English Jurist Henry De Bracton (d. 1268).* First attested in the United States in 'Documentary History of Maine Containing Baxter Manuscripts ..." *From "Random House Dictionary of Popular Proverbs and Sayings" by Gregory Y. Titelman. Roman poet Persius (A.D.c 58),*
>
> *"Meet the malady on its way."Prevention is so much better than healing, because it sauces the labor of being sicke" Thomas Adams's ‘Works’ - 1630.*

Sternberg (2000) uses the term ‘success intelligence’ to describe the ability to achieve success in life, given individual personal standards within a given sociocultural context.

The possibility to achieve success depends on the individual’s ability to capitalise on strengths and or correct compensation for weaknesses through a balance of analytical, creative and practical skills. Sternberg says in order to adapt, shape and select environments, gifted people do these at a higher level than do others. Sternberg stresses that gifted individuals have a superior aptitude to interact with their environment and to utilise their abilities. Whether the gifted maximise their strengths is dependent on their environment including the family, school and ***sociocultural*** context.

Neihart et al. (2002) found no evidence of social or emotional vulnerabilities or flaws unique to intellectually gifted learners or to those with high creative potential; but they do state social and emotional problems related to giftedness occur, and they most frequently reflect the interaction of an ill-fitting environment with an individual’s person characteristics. It is this flawed interaction between the gifted individual, their family, school, peers and culture, that impact on social and emotional development.

Therefore, using Sternberg's 'successful intelligence' as a focal point, the question that needs to be addressed is – '*What can education do to help non-neurotypical gifted SEND Students be successful in ill-fitting environments*'?

It is the researcher's response to the above question, that again highlights the UN's 'Child's Rights Charter' – 'The Child has a right to be heard' - "Allow the child a Voice; Listen to the Child."

Neihart et al. (2002) identified numerous researchers who agree that talented students are subject to unique stressors and vulnerabilities to difficulties with social and emotional adjustments (Genshaft, Greenbaum et al. 1995; Hoge and Renzulli 1993; Hollinger 1995, Silverman 1993; Webb, Meckstroth et al. 1982); and gifted/indifferent children and youths have a similar collection of problems identified by numerous researchers (Webb 1993; Clark 1983; Silverman 1993). Linda Silverman says gifted students have complex thought processes and emotions that are mirrored in the intricacy of their emotional development.

'Idealism, self-doubt, perceptiveness, excruciating sensitivity, moral imperatives, desperate need for understanding, acceptance, and love-all impinge simultaneously. Their vast emotional range makes them appear contradictory: mature and immature, arrogant and compassionate, aggressive and timid. Semblances of composure and self-assurance often mask deep feelings of insecurity. The inner experience of the gifted is rich, complex and turbulent. (1993) – (Montgomery (2003)

Dyssynchronicity

Terraiser (1985) describes dyssynchronicity as having two parts: ***internal*** refers to disparate rates of development in intellectual, psychomotor and affective development, i.e. Bastian having elaborate vocabulary and imagination and yet having an inability to write or read. The second part of dyssynchronicity is ***social***, in which the child feels out-of-step with the social context. i.e. Bastian keeping his advanced information or knowledge to himself, in case he gets ridiculed by peers of the same age.

Terraiser uses dyssynchronicity to describe the dilemma of being gifted and maintains, because of advanced cognitive ability, the gifted are faced with the dilemma of experiencing different mental, emotional, social and physical ages. This phenomenon coupled with intensity creates experiences that are qualitatively and quantitatively different for gifted students.

[If the researcher adds Bastian's (NS) Neurodevelopmental Syndrome SETD 5 and DCC into the equation, we get an even more skewed complexity, no data sets and no measurable matrixes - which is what this report is trying to adequately articulate and achieve, hence the overviewing of the clinical articles in support of Bastian's complexity.]

Terman's (1931) classic study of intellectual gifted individuals addressed the issue of dyssynchronicity. Precocity unavoidably complicates the problem of social adjustment. For example; Bastian a child of 12 years (June 2016), has a mental age of 16; however his cognitive ability is set at age 8. This is a complex and inconceivably difficult situation.

Selected characteristic that cause concern for gifted students

Persistence, intensity, perfectionism and sensitivity are characteristics that can cause considerable concern for gifted students. **Persistence** is viewed negatively by both parents and educators when the gifted child's persistence conflicts with established or set times for responsibilities; this is often referred to as being stubborn.

Intensity whether intellectual, emotional, sensual, imaginational or psychomotor as described by (Dabrowski, 1964, 1972) usually positions gifted students in conflicts with demands and expectations of the environment at home or at school. Dabrowski calls these intensities 'overexcitabilities' and research comparing 'overexcitabilities' (OEs) has found a greater incidence of OE's in gifted children and adults in comparison with other populations. When parents and educators fail to understand the overexcitabilities of students, the students' behavior may become even more intensified and or result in behaviour disorders or emotional disturbance.

Intellectual intensity can manifest itself with gifted children asking probing questions becoming preoccupied with theoretical problems, displaying an avid desire for knowledge about a given single topic and wanting to analyse material.

Emotional intensity can result in great intensity of feeling including concern with death, fears, anxieties and depression. Including a concern for others and a high wanting to be in the seen as the only one, or seeking sensual outlets, like; touching things, tasting and smelling.

Psychomotor intensity can be noted in a love of movement and speech, restlessness and impulsive activity.

Imaginational intensity can be associated with inventiveness, vivid animated visualisation and the use of images and metaphors in verbal expression.

Perfectionism as a characteristic in gifted students results in dissatisfaction with school work and work around the home; often giving up too soon.

Importance of accurate and appropriate feedback

When gifted SEN students receive feedback form parents and or school personnel that ‘they’ are the problem, gifted students without appropriate coping mechanisms can begin to feel estranged from peers and school and they begin to exhibit behaviour disorders and be classed as emotionally disturbed. We can ask many questions to address these behaviour issues, one of which, “Do ‘ill-fitting environments’ of school, family and community manifest behaviour disorders?

[It is the researcher’s hypothesis, that having lived with a complex SEND child for 13$^{3}/_{4}$ years (April, 2017) worth of experiences, that yes, ‘ill-fitting’ environments do lead to behaviour disorders, which is further supported by Bastian’s 7 yearlong psychological therapy under the CAMHS NHS Clinical Psychoanalytical Service.]

INTERVENTIONS WITH TALENTED AT RISK POPULATIONS WITH EMOTIONAL AND BEHAVIOURAL DIFFICULTIES

Ken W. McCluskey, Philip A. Baker, Mike Bergsgaard and Andrea L.A. McCluskey

Creative Problem solving in combination with mentoring, career awareness and other interventions have been used to carefully reduce the recidivism rate in the cases of Canadian inmates (Second Change Programme) so as to reclaim and support underachieving children.

> "If education is always to be conceived along the same antiquated lines of a mere transmission of knowledge, there is little to be hoped from it in the bettering of man's future. For what is the use of transmitting knowledge if the individual's total development lags behind"? - [Maria Montessori (1949), *The Absorbent Mind*]"

The cost of things gone wrong

'Crime and bad lives are the measure of a State's failure, all crime in the end is the crime of the community', said H.G. Wells (1905) in *A Modern Utopia*. Educational underachievement carries with it an ***emotional cost***. Since high school dropouts generally have a tough time obtaining and holding down jobs and 'in the case of SEN children – adverse and or unsuitable school placements could end up having more of a detrimental, emotional, psychological and financial effect on all concerned and not just the child in question. The government will ultimately pick up the cost therefore in terms of providing remedial actions by all connected public services'.

Although it may be impossible to quantify, there is also the social cost of what might have been. 'What is the 'cost' of a symphony unwritten; a cure not discovered, or a breakthrough not invented? In today's complex world, and in preparing for tomorrow's certainly more complex one, we can scarcely afford to waste "talent capital" of any sort.' (McCluskey and Treffiger 1998: p216).

When considering the overall state of affairs, we're reminded of the words of an old commercial: 'Pay me now, or pay me later.' Thinking it better to prevent than to lament, we decided long ago to attempt to make a difference by focusing on the at-risk domain.

The literature, as researched by Diane Montgomery (McCluskey et.al) work in a variety of settings, convinced them that there is an abundance of untapped potential out there, and far too many young people falling through the cracks, as it were. Due to lack of opportunity, "or Local Authorities not providing for SEN needs or Local Authorities/ (The UK Government) not taking accountability for their ill-fated actions" it appears many 'diamonds' are destined to remain 'in the rough' unless we can begin to intervene in a productive way. Creative Problem Solving (CPS) has provided one mechanism for dong precisely that. - *Diane Montgomery (2003) (Gifted & Talented Children with Special Education Needs)*

At this point the Article –

> *'Mum's fight to keep her Kids: Coventry Council was criticised by a judge for its treatment of a family who were threatened with having their children taken in care. (7 Oct 2010 - Updated 20:37, 25 Apr 2013 – Les Reid)'*
>
> It is not just the financial cost to the family, but the emotional and psychological damage that follows in the years thereafter. Governments and their Local Authorities are accountable to none; in that they are willing to spend hundreds of thousands of pounds even millions of pounds on a cases' with little resolve, [to either party] and even collapsing. The cases speak for themselves, with Bastian's case in particular, leaving a trail of untold damage in its wake.
>
> The ***true*** cost on the tax payer '*Best use of Resources*' is not just the cost of the legal cases', but the aftercare, the prolonged sufferance that ensues. The initial cost to the tax payer or even the family may seem high, however add to that, the after care plans and packages so as to mop up the damage, often rolling on year by year, turn into spiraling avoidable costs, thus taking away and or using up vital resources for or on other cases that are priorities. These wasted costs far outweigh the initial sum of money needed for the specific provisioning, yet the funding is deemed appropriate when being spent on avoidable caseloads, were the correct legal procedural processes applied at the beginning.
>
> The researcher asks: Is it the case, that funding at Local Authority level needs to be spent within the tax year, and spent frivolously, just so that the Local Authority can account for spending the funds, so as to secure it for a further year. Budget funding needs to be spent within the year, if not, the following tax year, well see the funding being allocated elsewhere, as it cannot be transferred to the following tax year. 'This is known as quick irrational spending, so as to secure all further allocated funds year on year.'

Reid goes on to report:

> The mother of three children who were for years threatened with being taken into care made an emotional plea before the council's court case spectacularly collapsed – costing taxpayers £500,000.
>
> The mum accused of lying about her children's illness and subjecting them to unnecessary medical examinations, said: "Only parents who love their children could cope with the life we lead.

“Support rather than relentless criticism from the local authority would be helpful.”

Her moving comment as part of High Court hearings was quoted in the published judgment of Judge Clifford Bellamy.

‘The Judge ruled Coventry City Council should be named as the authority which had “fallen below accepted standards” in pursuing the court action – without properly assessing flawed evidence provided for it by a medical expert.

One advocate who offers support in court to families told us the family courts too often rely on the assessment of a medical expert commissioned by the council – preferring it over contradictory independent expert advice.

‘The Judge was also scathing of the council’s failure to assess its lack of evidence before the council withdrew its court application, costing city taxpayers £200,000 with a further £300,000 paid in legal aid to the family.

EVERY CHILD CAN LEARN
Using Learning Tools and play to help children with development delay
Katrin Stroh, Thelma Robinson and Alan Proctor

2008

Therapeutic work with parents

It is generally recognised that confident parenting in a warm, loving, secure environment provides the ideal conditions for the development of learning, communication and emotional growth of the young child. In such an environment, pleasurable responsiveness and mutual exchanges or ‘intuitive parentese’ (Trevarthen and Aitken, 1994) are a natural part of the young child’s early experience. Of course, this family environment is also available to children with development delay.

However, the emotional reciprocity between parents and their delayed child may be late in developing with a neurologically impaired child, and may be weak, and fractured with genetic, physiological, biological and psychopathological problems. These babies as they mature into young children and adolescents cannot easily be comforted and do not always feel secure in their environments, despite all their parents’ efforts to offer the best possible care and nurturing.

Therefore, parents need support and understanding, to help them make sense of the different parenting experiences which are associated with a delayed child, thus collaborative work with all parents is essential if not critically essential.

Collaborative work with parents

By working collaboratively with parents, professionals hope to dispel their initial hesitation. ***Parents, who know their child so well, are the catalyst for the transfer of information and the necessary integration of the Functional Learning which is worked into the daily life of the family.***

With support, they can discover their own creativity and newfound skills in developing ideas for working with their child. As parents watch their child’s positive responses, the mutual pleasure and responsiveness felt by parents and child, helps to sustain and support them as they adjust to the new parenting strategies. ‘This is particularly pertinent when parents implement continual strategies for their developing SEN Child.’ As Daniel Stern (1985) puts it, ‘Organizational change from within the infant and its interpretation by the parents are mutually facilitative.’ Sharing the anguish as well as the positive delight, humour and laughter, as the child starts to learn and communicate, is a bonus for parents and professionals.

A COGNITIVE APPROACH TO LEARNING DISABILITIES
Social and emotional considerations with the learning disabled

Reid and Hresko

1981

[Willicott, (2016) "When starting to choose a SEND school placement, all professionals including the parents, who are, by far the most experienced expert, need to focus on the whole schooling environment and not just the provision, thus always keeping the chosen placement directly in line with their child's holistic individual needs and personal views; so as to avoid repeated costly placement breakdowns, which affect, not only the child, but the Local Authority, the school NHS and further support services."]

"Few cases of learning disorders are without emotional difficulties." (Bryant, 1996, p. 271) The ramifications of this statement are overwhelming. Surely, there exists thousands of learning-disabled children and adolescents whose emotional and social needs have not been are not being met.

Approaches:

1. Ways in which learning problems coexist with emotional and social development.
2. Research findings on the emotional and social characteristics of learning-disabled persons.
3. The possibilities for intervention which are within the teachers (schools) purview. The authors (Stroh, et al.) do not agree with Abrams and Kaslow (1997) that the learning disabled have needs which extend beyond the academic that teacher must address. Schooling / Education is not just academia.

<u>Relation between learning disabilities and emotional problems</u>

Although learning disorders and emotional difficulties are related, the above relation needs clarification.

The researcher agrees, as with most cases the above is correct, however the researcher's hypotheses, "There are those who are by measure 'learning deficient' but, who are equally and simultaneously emotionally intelligent." (Willicott, J. 2016).

If the emotional disturbance is the cause of the learning problem, eliminating the emotional disturbance would ameliorate the learning problem. In the case of learning disabilities, however, this does not happen (Connolly, 1971). Although the child may become more accessible, therapeutic intervention is not expected to rectify the learning problem. Yet, the coexistence of emotional and social problems within the learning-disabled population has been recognised, and many argue that when they do occur together, differential diagnosis is often impossible.

Children are, for example, labelled learning disabled, because they fail to meet the society's needs for literacy, the demands of an educational system, and the requirement to be able to succeed in school.   When the child who cannot read is label, the negative characteristics are emphasized, while the positive achievements of the individual are often overlooked (Wright, 1974).

Perhaps it is one residual effect of the Protestant ethic (Bartel and Guskin, 1968) which colours perceptions of those who are unable to succeed and/or be contributing members of society. It is little wonder that children with learning disabilities, often described as "bad students," develop mechanisms of coping which affect their emotional and social development. There can be no denying that we all strive to some degree to fulfil what we perceive as others' expectations. Poor treatment by others often leads to evasiveness, under activity, and silence (Kronich, 1976).

The existence of a problem may very well be the result of the reactions of others (Algozzine, 1977). The effects of societal expectation, though focused on the learning-disabled individual, also affect significant others in the child's environment and these persons, in turn, affect the child. Determination of the worth of a child by the larger society necessarily affects the functioning of the family unit (parents, siblings, and often more distant relatives), causing them to question not only their child, but also their own abilities and worth.

'Factors that interfere with adequate emotional and social development may also be leaned. In some cases, the learning-disabled child may be placed with other learning-disabled children who have severe behaviour disorders. It is possible that the learning-disabled child might adopt their style of behaviour, especially if it is seen as effective behaviour.'

There can be no naive assumption that societal events occur in isolation. The complex integration of child and society must be recognised as the source of handicapping emotional problems. Often some thwarted needs in the growing child's emotional life will manifest themselves in undesirable behaviours, because of the child attempts to accommodate to the demands of the situation while still maintaining psychological integrity.

The effect of a damaged sense of self on the development of many disabled children has become of increasing concern (Blanck and Blanck, 1974; Buchholz, 1978; Giffen, 1968). Once a child learns that he or she has limited ability to initiate actions successfully, that child may become unable to act, may compensate by becoming aggressive, or may try to mask his or her inability by overcompensation (Rawson, 1973). If we gain notions of competence through recognition of what we ***can*** do, then the effect of conventional educational programmes, focusing on the weakness of the child, may sorely impede the achievement of feelings of competence.

It is not surprising that reports of severe anxiety and the need for support (Bender, 1967), as well as feelings of being unloved, permeate the literate on learning disabilities. (Wender, 1971)

The functioning of any individual is a function of interpersonal interactions and societal prescriptions. (Siller, 1976) Placed in situations which are too complex, many learning-disabled children revert to infantile patterns which were once successful (Eisenberg, 1967).

Passivity, dependency aggression, compensation, withdrawal, coping, shame and guilt are all possible reactions to the realisation that one is handicapped (Siller, 1976). Of these, perhaps the last two are the ones least frequently explored.

Placed in a situation where failure equals "stupid," "disappointing" or "bad" the learning-disabled child is constantly reminded of his or her *less than* adequate performance. Stress from guilt (for being inadequate) and shame (for not fulfilling expectations) may take a considerable toll.

Stress and tension often raise the frequency of ineffective behaviour and add to a cycle of disapproval, thoughts of inadequacy, and subsequently, more aberrant behaviour (Pohl, 1976).

Bastian highlights the above by adequately using his voice, which details his perception and self-awareness, especially when choosing and adapting to an environment and schooling institution.

The researcher copies the statement made earlier by Bastian:

Bastian's Statement of Belief and Self-awareness

Mommy: "Bastian, do you want to go to school?"

Bastian: "Yes, Mommy."

Mommy: "Bastian, if you had a choice, and your voice was heard, and taking into account all the schools we went to visit, which school would you like to attend?"

Bastian: "The School in Hemel Hemptead Mommy, called the Collett School."

Mommy: “Why have you decided on this school Bastian; can you explain?”

Bastian: “The Collett School makes me feel normal Mommy.”

Mommy: “Can you try to explain why this is Bastian?”

Bastian: “I like all people Mommy, it is just that The Collett School makes me feel safer and happier as I can be myself with feeling or being scared, because I know myself and what I want.”

Mark Carter’s (Barnet SCAN and CAMHS - NHS) Child Clinical Analytical Psychoanalyst reports (May 2014)

> *“His rare mix of strengths and difficulties (resulting from two rare genetic conditions) means that he would find a mainstream school to be a very challenging environment, but his apparent abilities would indicate that a special educational provision (such as Oak Lodge) School) would also be inappropriate. He can at times have a low self-esteem due to his worries about having something wrong with him and his frustration with this, which manifest difficulties in some other areas.*
>
> *Our concern would be that when surrounded by individuals who are far more disabled that he is, in a special educational provision, his self-esteem would be adversely affected, particularly as he has only been in a mainstream educational environment so far in his school career. Such a change in his environment at the important transition point may then pose a risk to not only his emotional well-being, but also on his developmental push to move forward – which can often be difficult for young people who have to struggle with disability.*
>
> *Bastian will benefit from a mixture of mainstream and specialist teaching to support his cognitive, educational (academic), emotional and social skills, which in turn will improve his motivation and self-esteem as well as support his emotional well-being.*

One area of emotional development that is just beginning to be investigated is the study of temperament. Temperament is a very difficult entity to define adequately. It refers to “within-child” stylistic characteristics which affect the relationships of the child and his family, and which determine in part, his response to the environmental and experimental demands of socialisation within the environment. (Keogh and Pullis, 1980)

These unique individual differences also affect what will be extracted from the social environment. The course of the predispositions is determined by complex interactions with the environment, but the environment in turn is also affected (Buss and Plomin, 1975). Analysis of temperament characteristics may prove valuable for understanding and predicting emotional and social development.

Some researchers have identified characteristics (such as approach or withdrawal, adaptability, threshold or responsiveness, intensity of reaction, quality of mood, distractibility, attention span, and persistence) which have been used to cluster children into groups of easy, difficult, slow-to-warm children (Thomas and Chess, 1977). These groups have proved relatively stable, and in the case of the difficult child, have shown some correlation with later behavioural problems. Though research has been done with at-risk populations (Lambert & Windmiller, 1977) mentally retarded populations (Chess and Korn), and preschool populations (Lewis, 1977), no studies have been undertaken with learning disabled children.

The questions surrounding temperament are far from settled. As noted by Keogh and Pullis (1980), while the interactionist focus of the temperament concept is appealing, questions remain regarding definition, underlying traits, the organisation of traits and changes in organisation, the effect of various parental variables, the type of data to be collected in studies, and the concept of its basis – biological or constitutional.

In summary, many of the emotional and/or social problems of learning-disabled children are likely to result from the interaction of the child and society. A child who cannot read or calculate is not a problem in a society in which such skills are not valued; particularly when, the prognosis for achievement and adult well-being is often dependent on a loving, supportive early environment.

Research on emotional and social development in the learning disabled

The research on emotional and social development can be separated into several specific areas:

1. Teacher/child interactions
2. Self-concept and academic achievement
3. Juvenile delinquency
4. Human figure drawings
5. Nonverbal kills and social perception
6. Parent and family concerns

For the purposes of this report, the researcher will focus on the teacher/child interactions.

> Teacher/Child Interactions
>
> *Teachers may have a great deal to do with fostering negative self-regard in the learning disabled*. Bryan (1974) found that learning disabled children had as many interactions with peers and teachers as ‘non-learning’ disabled children.
>
> Yet, for the learning disabled, over one-half of the teacher interactions revolved around work-related issues, while, for the ‘on-learning’ disabled, only one-quarter of the interactions did so. With respect to the reinforcing quality of the interactions, (Bryan) found more negative reinforcement in the interactions between teachers and learning-disabled children than between teachers and ‘non-learning’ disabled children.
>
> With regard to teacher expectations, it appears that teachers form negative *pre-expectations* of learning-disabled children even before instruction takes place (Foster, 1976; Foster, Schmidt, and Sabatino, 1976). Not only were teachers’ expectations negatively biased toward children they were told were learning disabled, but these negative expectations continued even after evidence to the contrary was provided (Jacobs, 1976, 1978). Others (Sutherland and Algozzine, 1979) have also noted that simply labelling a child as learning disabled resulted in differential treatment.

It appears, then that learning disabled are viewed as socially and/or emotionally different by both teachers *and* peers, that they are less likely to be chosen by others as friends and more likely to be rejected, that teachers see them in a negative light, and that their aggressiveness works against them.

CHILDREN'S SOCIAL AND EMOTIONAL WELLBEING IN SCHOOLS

A critical perspective

Debbie Watson, Carl Emery, Phillip Bayliss

2012

INCLUSION IN SCHOOLS

Being well

Educational philosophy emanating from Aristotelian or humanist formations locates education within a discourse of moral, personal and social development.

The purpose of supporting SMSC (Spiritual, Moral Social and Cultural) development was underpinned by a sense that by promoting healthy societal values, the ills of society could be diminished and that schools were a central institution for the promotion of values. The central role of the schools in promoting ‘healthy values’ was emphasised in a set of qualitative indicators of the ethos or hidden curriculum pursued by the school and staff (‘climate of values’ of the school) (OFSTED, 2004).

This view had all changed by 2008, and OFTSED’s (The Office of Standards in Education) consultation document was to develop indicators of a school’s contribution to well-being so as to promote SMSC. The role of schools is limited as ‘Parents have the biggest influence on children’s well-being’ (OFSTED, 2008).

‘Mainstreaming’ as a concept appeared first in the US in the early 1990’s and was seen as a ‘neutral’ term for the educational placement of disabled children in the ‘mainstream’. This term did not have the negative implications of ‘integration’ derived from the experience of desegregation of school in the US.

For non-disabled low achievers in schools (and the derivation of the concept of ‘special educational need’), the main changes have been in the areas of categorisation, as learning failure, has come to be understood with respect to a range of psychological and socio-cultural factors.

Inclusion as policy

Policy, with an inclusion focus, is based on objective views of measurable phenomena: the answer lies in the ‘‘maxim’; to improve something, first measure it’. Even the decision to measure helps set direction and priorities by demanding a degree of consensus on what is to be measured – That is, on what constitutes progress.

Returning to the discussion of schooling, the UK government has never produced policy to influence human relationships in schools (and, following the Organisation for Economic Co-operation and Development's [OECD's] original caveat (OECD, 2009), it is difficult to see how such policy could be framed).

However, since 1990's, the government has adopted a policy of inclusion to address the concern of minorities within society, especially those deemed to have special educational needs, disabilities or who are at risk of social exclusion and who experience cumulative disadvantage. In the sense, the policy framework has been 'anti-discriminatory', and the discourse has shifted to one of equal opportunities and rights.

Inclusion has been enshrined at the same time that segregation and discrimination have been rejected. Articulations of the new developments in ways of thinking, in policy and in law include: the *UN Convention on the Rights of the Child* (UN, 1990); the *UNESCO Salamanca Statement* (UNESCO, 1996); and the UN *Convention on the Rights of Persons with Disabilities* (UN, 2006).

Since the period from 1981 to present, successive UK governments have implemented various inclusive policies, which match the global framework adopted by the United Nations (UN), especially the Salamanca Statement of 1994 (UNESCO, 1994). **However** even with a plethora of inclusive policies, Roulstone and Prideaux (2008) argue that: 'on two key measures of the number of disabled children educated in mainstream contexts and the number of school exclusion affecting disabled children, there is no significant evidence of improvement'.

In the case of [Bastian Willicott v United Kingdom -- 17275/15-39415/16] and as highlighted by this report, it is not only evident that the UK lack significant improvement, in that Bastian's voice was not heard, and it being documented, the UK simply 'inadvertently' fail to act on the most basic of rights.

The major problem with functionalist evaluations of education is the assumption that the norms and values being inculcated are equitable, shared and advantageous to all. Parallel assumptions suggest that all children begin their educational journey at roughly the same starting point. Arguably, neither of these points are accurate reflections of the nature of educations in a competitive industrial society (Roulstone and Prideaux, 2008)

The outcomes of Warnock's (1978) report and subsequent legislation, even though it advocates integration for children with disabilities, has been continuing special education (whether this takes place in a special school, special class or unit) where children are educated separately.

Inclusion as a set of placement decisions

The House of Commons Select Committee on Education and Skills (HM Government, 2006, s61) noted: ‘the debate over provision has for too long focused on an unhelpful interpretation of inclusion as a place (that is, special or mainstream) rather than on what the pupils achieve’. Ellis et al (2008) noted that an understanding of inclusion was predicated on place: usually mainstream versus special school.

Placement decisions are subject to the Foucauldian System of producing ‘docile bodies’, which are predicated on processes of hierarchical observation, normalising judgement and examination (Foucault, 1991). Such processes, as we have argued earlier, are based on judgement of capacity and contingent behaviour. The placement of a child is subject to quasi-legal processes (in England) of identification of need through procedures of assessment / diagnoses.

Such processes are **controlled** by Educational Psychologists and Local Authorities. In the current austere climate of which it could be argued as merely ‘political austerity’ rather than economic austerity enforced by the ruling / governing Conservative Government – the said provision and or ‘legal’ processes are driven by budget cuts; and therefore before the case is even heard, Educational Psychologists are automatically dismissing a SEND child and their individual needs.

This is highlighted by the BBC article:

BBC NEWS ARTICLE

CASH SHORTAGE FOR SPECIAL EDUCATIONAL NEEDS' SUPPORT

By Katherine Sellgren BBC News education reporter

> ***Schools in England are struggling to support the 1.1 million pupils with special needs or disabilities (SEND) in mainstream classrooms, a report says.***
>
> *A survey of 1,100 school leaders found delays to assessments, insufficient budgets and cuts to Local Authorities were hampering the ability to cope.*
>
> *The study by [The Key], which provides leadership and management support to schools, calls for increased funding.*
>
> *The government says it has increased funding for those with "high needs".*
>
> ***Department for Education (DfE) statistics*** *published last year (2015) showed there were more than 1.3 million children in England - 15% of pupils - identified as having special educational needs or disabilities.*

How are children with special educational needs supported?

Of these, 1.1 million are in mainstream schools rather than special schools.

The research by [The Key] suggested:

- *82% of mainstream schools in England do not have sufficient funding and budget to adequately provide for pupils with SEND*
- *89% of school leaders believe cuts to local authority services have had a detrimental impact on the support their school receives for pupils with SEND*
- *Three-quarters of schools have pupils who have been waiting longer than expected for assessment of special educational needs or an education, health and care plan*
- *88% of school leaders think initial teacher training does not adequately prepare teachers to support pupils with SEND*
- *The report follows government reforms, which came into effect in September 2014, that aimed to put each child and their family at the centre of discussions about support offered*
- *Under the Children and Families Act 2014, Special Educational Needs Statements and Learning Difficulty Assessments (LDAs) have been replaced with Education, Health and Care Plans (EHCP) covering people up to the age of 25*

Primary strain

The Key survey suggests primary schools are under the most strain when it comes to providing for pupils with SEND. Eight in 10 primary school leaders said their budget was insufficient, while seven in 10 at secondary school level raised concerns about funding. Nine in 10 at primary level have had the support they receive for SEND provision affected by cuts to their local authority, while this was the case for eight in 10 secondary leaders.

Delays in assessment of SEND and long waits for EHCPs also appear to be more common for children of primary school age. Eight in 10 primary schools have pupils who have been waiting longer than expected, while the figure is just over six in 10 at secondary schools.

Fergal Roche, chief executive of The Key, said: "A year on from major reforms to the national system for SEND provision, these findings represent an important wake-up call from school leaders. "Schools need adequate funding and a holistic, well-co-ordinated and resourced system of support behind them to provide effectively for children with SEND."

Cllr Roy Perry, chairman of the Local Government Association's children and young people board, said: "We were clear with the Department for Education at the time that implementing the SEND reforms in the Children and Families Bill was significantly underfunded by the government and this has been borne out in reality.

"Councils are working hard to ensure all children and young people are being moved from SEND Statements of Education to EHCP by the deadline of 31 March 2018, but the transition process is complex."

The DfE spokesman said: "Schools have a vital role to play in this work, which is why we've protected the overall school budget and increased the funding for children and young people with high needs by over £90m this year (2016). "Ensuring teachers are trained to have an understanding of the needs of pupils with SEND is a key part of our drive to give all children access to the education they deserve." SEND training will form part of the new core content for initial teacher training, the spokesman added.

Inclusion as personal experience

The final standpoint on inclusion presented by Ellis et al (2008) was that of the ‘consumer’. In all the discussion so far, the psychological effects of the road from exclusion to inclusion (Andrews and Lupart, 2000) have not been addressed.

The researcher highlights Bastian’s case, in so far, that he has had to be Home Educated so as to protect his emotional stability and mental well-being; so as to keep the psychotherapy progress from unravelling.

In Ellis et al’s analysis of inclusion the final section addressed the psychological aspects of inclusion as they relate to personal experience. How do pupils (and their parents) experience inclusive education? How does their experience relate to the concept of inclusion?

Non-professional stakeholders (particularly parents) see inclusion as being linked to care, security, social acceptance and wellbeing (Yssel et al, 2007; Runswick-Cole, 2008); others (not least children and young people themselves) see it in terms of friendships and positive peer relationships (Woolley et al, 2006) or of the negative impact of bullying (Norwich and Kelly, 2004).

However, in contemporary drivers to reduce inclusion to measurable indicators, some commentators claim that ‘the views of disabled youngsters and their parents regarding what the desirable consequences of inclusion should be, have been disregarded’ (Allen, 2004, p419). This quote from Julie Allan, again begs the question of what the ‘desirable consequences of inclusion’ are.

The labour Government under the leadership of Tony Blair PM (Prime Minister and Right Honourable MP, got ‘rid’ of the ‘middle grounded school placement’ – [not mainstream or special] in favour of inclusion, leaving parents and children little or **no choice.**

There are links between education and psychological well-being and health (WHO, 2004), but very little comparative research into differences between inclusive and segregated (special) education. Early research (Wade and Moore, 1993) produced generally negative results about pupils’ expectations of special education. More recently, Heiman noted that pupils with learning difficulties in special schools ‘felt lonelier than student in other groups.

Meyer, (2001), demonstrated how difficult it was to provide any strong understanding on the social impact of placement decision for vulnerable children. On balance, she presents data to suggest that disabled children’s experiences of inclusive education can be descried as ‘helper-helped. Bayliss (1995) showed that interactional behaviour could also be described in this way. The lack of comparative research in this area makes drawing any kind of conclusion highly problematic.

These studies relate to the quality of interpersonal relationships, other studies, which looked at a broad range of factors (relating to achievement and self-reports), presented different findings. For example, in 2006, OFSTED reported that the most important factor in determining the *best outcomes* for pupils with learning difficulties and disabilities (LDD) *was not the type, but the quality of the provision* (OFSTED, 2006). This followed the 2005 OFSTED report Promoting Emotional Health and Well-Being in Schools (OFSTED, 2005), which examined the vital role played by schools in promoting emotional well-being of their pupils.

These reports explored the psychological effects of education with respect to mental health (OFSTED, 2005) and inclusion (OFSTED, 2006) in terms of placement. The second report’s full title is *Inclusion: Does it Matter Where Pupils Are taught?* And both reports emphasised the qualitative aspects of schooling that impact on achievement and well-being.

The link between well-being and education is well attested to. A positive school environment can lead to greater wellbeing (Ravens-Sieber et al, 2004). The OECD’s (2004) review children’s well-being across Europe claimed that if the experience of children and their parent’s carer was focused on physical, emotional and social well-being, then these factors impact on both achievement and health. The strong independency between learning and well-being argues that educational processes need to be inclusive.

Where schools are working with groups that do not exhibit solidarity or belonging exclusively can break the link between learning and well-being and result in disaffection, alienation and ill being. Thus, inclusion becomes a complex phenomenon: the processes [involved in inclusion] are psychosocial in that they encompass the sociology of group composition and change, social roles, interpersonal understanding, friendship, social stratification and the dynamics of social justice, as well as the psychology of human development and behaviour.

EMOTIONAL AND MENTAL WELLBEING

MEETING CHILDREN'S BASIC HEALTH NEEDS: From patchwork to tapestry Children and Youth Services Review

Russ, Garro, Halfon

2010

IN the United States of America - Few would deny that if a system were to be designed de novo to meet children's basic health needs, it would be radically different from the confusing and fragmented patchwork of programs in place today.

While Medicaid and the Children's Health Insurance Program (CHIP), have improved access to care, increased use of health care services, and reduced unmet health needs for low-income children, the impact of these programs on the quality of health care, and on children's health outcomes is less certain.

Meeting children's basic health needs is an important goal of any society. However, countries vary significantly in their definitions of those needs, beliefs about who is responsible for meeting them, and in the proportion of resources allocated to meet those needs. Despite it's great wealth, and unbridled expenditure on health care in the later years of life, the United States has made only relatively modest investments in the early childhood years, especially when compared with Scandinavian countries (Bennett, 2008) The United States is consistently among the lowest summary rankings of child well-being in cross-country comparisons (Wise & Blair, 2007).

This situation is particularly surprising given the growing body of evidence demonstrating the links between adverse early life events and experiences, and the development of poorer health in young adulthood (Currie, Stabile, Manivong,& Roos, 2008; Shonkoff & Phillips, 2000) and chronic diseases in mid-life (Kuh & Ben-Shlomo, 2004; Barker, Osmond, Forsen, Kajantie, & Erikson, 2005; Keating & Hertzman, 1999; Forrest & Riley, 2004).

Evidence is also accumulating for the powerful links between health, especially mental health in childhood and later economic well-being (Currie, Stabile, et al., 2008). In this paper, they explored the growing mismatch between the understanding of the importance of health in the early years, the changing epidemiology of childhood illness, and the health care policies that are currently in place to meet children's basic health needs.

The analysis is guided by the Life Course Health Development Model (Fig. 1; Halfon & Hochstein, 2002) as a conceptual framework. In this model, health develops as a consequence of multiple factors that operate in genetic, biologic, behavioural, social and economic contexts. Health is not static, but results from the cumulative influence of multiple risk and protective factors over time (Halfon & Hochstein, 2002; Kuh & Ben-Shlomo, 2004).

Exposure to risks during critical and sensitive time periods of development, such as early childhood and adolescence has particularly powerful effects. The model supports the emerging consensus around the importance of social determinants of health and their variable impact at different stages of development (Marmot, Friel, Bell, Houweling, & Taylor, 2008), while emphasizing the importance of ensuring children's social and emotional well-being in addition to their physical health.

The model also suggests that optimizing and promoting health in the early years could have profound positive effects on health in later years.

Chronic illness and neurodevelopmental disabilities

Despite reductions in childhood mortality, rates of acute illness, and pediatric hospitalizations (Wise, 2007), the prevalence of chronic illness appears to be increasing (Wise, 2007; Newacheck, Budetti, & Halfon, 1986) with 6.5% US children experiencing some degree of disability (Newacheck & Halfon, 1998) and 12–18% having special health care needs (Bethell, Read, Blumberg, & Newacheck, 2008). Trends are particularly concerning for mental and developmental health, with increasing prevalence of disabling mental health conditions (Halfon & Newacheck, 1999), and autism (Newschaffer, 2006).

Child health policy in historic and social context

Children's services are delivered through a patchwork of programs created over the years in response to a variety of historic and political forces. Program eligibility is determined through a series of confusing and complex requirements. Some programs such as Medicaid are entitlements, with eligibility based on meeting certain criteria e.g. age, income, resources, and immigration status.

Second, political compromise has tended to result in policies that address only some of the needs of children, including those living in poverty, and those with demonstrated disabilities. While children that fall into these defined categories are eligible, at least on paper, for relatively generous benefits, others including the near-poor, and those who have not yet developed overt manifestations of chronic health conditions, have been relatively overlooked. Existing child health policy has resulted in a patchwork of programs that fail to fully address children's health needs.

Low income children, particularly those with special health care needs, and those that lack health insurance, are especially vulnerable.

The Grand Chamber of the European Court of Human Rights has stated that:

> The human rights of children and the standards to which all governments must aspire in realising these rights for all children are set out in the Convention on the Rights of the Child… The Convention spells out the basic human rights that children everywhere – without discrimination – have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life.
>
> It further protects children's rights by setting standards in health care, education and legal, civil and social services. States parties to the convention are obliged to develop and undertake all actions and policies in the light of the best interests of the child (Article 3 – CRC – Child Rights Charter).
>
> Moreover, States parties, have to ensure that a child is not separated from his or her parents against their will unless such separation is necessary for the best interests of the child, and respect the right of a child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests (Article 9).(*Sahin v Germany 2003*)

THE RELATIONSHIP BETWEEN EMOTIONAL INTELLIGENCE AND PSYCHOLOGICAL WELLBEING

Carmeli, et al.

2007

Purpose – Theory suggests that highly emotionally intelligent individuals are likely to experience psychological wellbeing at a higher level than individuals who are low in emotional intelligence. The above study aimed to aimed to examine the relationship between emotional intelligence and four aspects of psychological wellbeing (self-acceptance, life satisfaction, somatic complaints and self-esteem).

Design/methodology/approach – Data were collected from employees through two different structured surveys administered at two points in time. Findings – The results of *four* hierarchical regression models provide, in general, support for the positive association between emotional intelligence and psychological wellbeing components, self-esteem, life satisfaction, and self-acceptance. Only marginal significant support was found for the negative relationship between emotional intelligence and somatic complaints.

The 1990's were witness to a growing interest on the part of scholars and practitioners alike in the construct of emotional intelligence. The interest reflects the theoretical proposition that individuals who are high in emotional intelligence are likely to experience more success in work-related and non-work aspects of life than low-emotionally intelligent individuals. Despite the surge of interest in emotional intelligence, researchers acknowledge that this concept is still in its early stages (see Davies et al., 1998; Mayer et al., 2001; Zeidner et al., 2004).

Additionally, empirical evidence is still needed to determine the importance of emotional intelligence for explaining emotional reactions and behaviours (Jordan et al., 2002) and achieving success in various aspects of work (Abraham, 1999) and life. Despite the claims that emotional intelligence may contribute to explaining emotional deficits, little research has been produced that demonstrates the value of emotional intelligence in this respect (Mayer et al., 2002; Palmer et al., 2002).

Theory development and hypotheses 'Emotional intelligence' is rooted in early works on emotions and social intelligence. The foundation of emotional intelligence can be traced back to Thorndike (1920) (note that others have raised doubts as to whether Thorndike could be said to propose or support the concept of emotional intelligence (see Landy, 2005)), Moss and Hunt (1927), Guilford (1956), Vernon (1933) and Gardner's (1983) works on social intelligence.

These scholars suggested that social intelligence is another facet of intelligence (Thorndike, 1920). Gardner (1983) proposed a conceptualization of interpersonal intelligence – the competence to understand other people, and intrapersonal intelligence – the competence to understand the self and apply it effectively in life.

Psychological wellbeing is a complex and multidimensional construct. In its simplest form, psychological wellbeing represents “a generalized feeling of happiness” (Schmutte and Ryff, 1997). It represents wellness that is conceived as “progressions of continued growth across the life course” (Ryff, 1995). This view reflected an emphasis on life satisfaction and happiness. A more accurate approach is to view wellbeing as a construct that represents aspects of positive functioning (Ryff, 1995).

Discussion - The present study joins a growing body of literature seeking to determine the role of emotional intelligence in explaining individuals’ success and wellness. More specifically, the goal of the study was to examine the relationship between emotional intelligence and various aspects of psychological wellbeing among employees who work for diverse organizations in Israel.

The findings of this study support the core proposition of the theory; namely, the significant role of emotional intelligence in experiencing a sense of wellbeing. This study found that individuals reporting higher EI (Emotional Intelligence) reported higher levels of life satisfaction, self-acceptance, and self-esteem than individuals who are relatively low in emotional intelligence.

SCHOOL DIFFERENCES IN ADOLESCENT HEALTH AND WELLBEING: FINDING FROM THE CANADIAN HEALTH BEHAVIOUR IN SCHOOL-AGED CHILDREN STUDY

Saab and Klinger

2010

The goal of the above study was to assess the relation hip between student- and school-level factors and student health and wellbeing outcomes and to estimate the variability present at each of the student and school levels for each of three selected health-related outcomes.

Adolescents spend a substantial portion of their lives in school settings. Their experiences in schools not only affect their academic development but also strongly influence their social-emotional and physical health development, both positively and negatively (Wells, 2000). **Specifically, students' health behaviours and their views of themselves are related to their lives in school** (Anderman, Maehr, & Midgley. 1999). **In addition to the direct teaching of academic skills, schools provide opportunities for adolescents to develop relationally, emotionally, and behaviourally in ways that often have lasting impacts on their lives** (Willms, 2004).

Given these important impacts of schools, it is not surprising that the values and expectations of society as a whole are reflected in our schools. Educators find themselves under constant demand to validate and legitimise their roles in a changing society, shifting the emphasis on the various outcomes of schooling. (Paulus, 2005)

Academic outcomes are certainly important facets of "effective schools" (Rutter, Maughan, Mortimore, Duston & Smith. 1979), but they are not the only ones that matter (Hargreaves, 2001). The shifting expectations of schools have resulted in efforts to address students' *physical and mental health* in addition to conventional academic outcomes.

In response, there has been an ongoing call for school reform efforts to incorporate affective (psychological and emotional) outcomes in conjunction with academic (cognitive) outcomes (Fitz-Gibbon, 2006; Hebrty. 1994; Huebner & McCullough, 20QO; Phillips, 1993; Weare ~ Gray, 2003). *These efforts may be particularly important because physical and mental health problems in childhood and adolescence may compromise academic functioning* (Field, Diego, & Sarders. 2001; Needham, Crosnoe, & Muller, 2004; Thies, 1999).

Moreover, it is becoming more apparent that *educational attainment is closely linked to health promotion efforts in school* (Paulus, 20 5), and how schools promote student wellbeing through their organisation and structure (Markham & Aveyard, 2003).

Earlier research by Knuver and Brandsma (1993), employing models that examined relationships at the student and school levels, found schools that were effective in the cognitive outcomes were also effective in promoting the affective outcomes.

Therefore, it is reasonable to state that the dimensions that constitute effective and good schools, and those that promote the health and wellbeing of students, may not discrete. These dimensions likely overlap, and efforts to improve student health through broad school interventions contribute to a school's educational aims (Paulus, 2005).

Comprehensive School Health initiatives and their European counterpart, Health Promoting Schools (HPS) have been proposed as having the potential to develop the positive health attributes of students (St. Leger, 2000), and their mental and social wellbeing (Lister-Sharp, Chapman, Stewart-Brown, & So den, 2000). HPS principles are rooted in social-ecological models that emphasize the need to address a setting's organisational and structural features (Dooris, 2004). However, there is a lack of operationalization of these dimensions, particularly as they relate to a *school's environment and its links with the community* (Deschesnes, Martin, & Jomphe Hill, 2003).

As such, identifying school factors and conditions that are associated with student health and wellbeing would be useful for developing HPS initiatives. In response to the need to identify such factors, this above study examines the relationships between student and school-level factors and student health and wellbeing outcomes. The work was guided by the following research questions.

- To what extent do student health and well-being outcomes vary across schools?

- What are the student-level factors that are associated with students' health and well-being outcomes?

- What are the school-level factors, as reported by administrators that are associated with students' health and well-being outcomes?

- Does the relationship between school-level and student-level variables vary across different school conditions?

Schools are increasingly recognised as social systems with the potential to enhance the health of their populations (Rowling & Rissel, 2000). These developments are rooted in social-ecological models of health that generally reflect a broad vision of wellbeing that encompasses physical activity, mental an emotional wellbeing, and social cohesion at both the organisational and community levels (Dooris, 2004).

Accordingly, the "**health promotive capacity of an environment must be defined in terms of the multiple health outcomes resulting from people-environment transactions**" (Stokols, 1992) and the environmental resources or constraints that could influence personal and collective wellbeing.

The underlying premise of HPS is that longer-term health improvements will only ensue if initiatives are integrated into a broader, multi-faceted health promotion strategy that supports sustained change and moves "*beyond the individual* to encompass the *school environment*, structural issues and organizational practice" (Inchley, Muldoon, & Currie, 200)

Results

Descriptive statistics

Correlations amongst the three outcomes-were low to moderate but statistically significant. The strongest correlation was between Subjective Health Complaints (SHC) and Emotional Wellbeing (EM) (r = 0.50). The correlations between Self-Rated Health and Subjective Health Complaints(SHC) (r = 0.30) and Self-Rated Health (SRH) and Emotional Wellbeing (r = 0.18), were relatively low implying that these measures may target different dimensions of health and wellbeing and that, the Subjective Health Complaints and Emotional Wellbeing scales may both be indicative of psychological wellbeing. Correlations among the school variables were low to moderate but significant and ranged, from 0.19 to 0.49.

Emotional wellbeing

Approximately 196% of the variance in students' Emotional wellbeing (EWB) existed between students and just 4% was between Schools.

Discussion and implications

The question, of if, and how schools make a difference to students' educational achievement behaviours and health, continues to occupy researchers, policy makers, and practitioners (Kirk, 2006; West et al., 2004).

Key findings of the above study are that while there were differences in the three health outcomes across schools, these differences were modest, accounting for only

2% - 4 % of the total variance in Self-Rated Health (SRH), Emotional Wellbeing (EWB), and Subjective Health Complaints (SHC), the study, identified both individual and school-level factors that are associated with students' reported health outcomes.

SENSE OF COHERENCE AND SCHOOL-RELATED STRESS AS PREDICTORS OF SUBJECTIVE HEALTH COMPLAINTS IN EARLY ADOLESCENCE:

Interactive, Indirect or Direct Relationships

Torbjorn, et al.

2001

The role of sense of coherence (SOC) on the relationship between adolescent school-related stress and subjective health complaints was tested with structural equation modelling. As part of the cross-national WHO-survey ‘Health behaviour in school-aged children 1997/98’ Norwegian representative samples of 1592 grade 6, 1534 grade 8, and 1605 grade 10 students completed measures on SOC, school-related stress and subjective health complaints.

Age-group comparisons revealed that the association between SOC and stress grew weaker with age, whereas the direct association between SOC and health complaints grew stronger. Not all students develop complaints from school-related demands has directed the attention to factors that moderate the perception of stress, and the adverse health impact of stress (e.g. Wagner & Compas, 1990; Ystgaard, 1997).

In adults, one of the stress moderators that has generated considerable interest is the sense of coherence (SOC), a global orientation to view life situations as comprehensible, manageable and meaningful (Antonovsky, 1987). In the original theoretical formulation Antonovsky (1987) proposed that SOC may influence stress and health in three ways: (1) SOC influences whether a stimuli is appraised as stressor or not; (2) SOC influences the extent to which a stressor leads to tension or not; and (3) SOC influences the extent to which tension leads to adverse health consequences.

While research on adults in part support these assumptions (for a review, see Antonovsky, 1993), the role of SOC in child and adolescent health is largely unexplored. With the view that school adaptation has an essential impact on a wide range of social, psychological, and behavioural outcomes, empirical evidence on the stress moderating role of SOC during adolescence may offer particular scope for the development of prevention policies.

SOC and stress appraisal

Unpredictable or incomprehensible life situations are potent sources of stress (Lazarus & Folkman, 1984). As a global orientation to life, the sense of coherence (SOC) will influence the degree to which people view life demands as chaotic and incomprehensible, or coherent and comprehensible. Through the confidence that

‘. . . The stimuli deriving from one’s internal and external environments are structured, predictable and explicable. . .’ (Antonovsky, 1987), individuals with a strong SOC will be less likely to perceive ambiguity in encounters with life demands.

In keeping with the hypothesis that a high SOC may help to appraise demands as non-stressful, studies on adult populations have reported moderate inverse associations between measures of SOC and measures of perceived stress. A review of these studies (Antonovsky, 1993) showed that that the associations are generally stronger for perceived measures of stress than for measures of stressful life events, suggesting a role in appraisal processes, and not in the actual exposure to stressful events.

> **[The researcher notions that the above SOC study adequately relates to that of Bastian’s stressors and most certainly by the way he perceives himself, which could indicate how the possible stressors would directly relate to imposed stress by his own admission when not being in the correct and safest ‘schooling’ and or environment placement especially where he didn’t and doesn’t feel like his normal self.]**

SOC and stress moderation

As a next step in the stress process, SOC has been suggested to influence coping expectancies in encounters with stress (Antonovsky, 1987, p.19). According to the transactional model of stress (Lazarus & Folkman, 1984), coping expectancies develop from secondary appraisal processes, where people assess the means that are available to deal with the stressful condition. As a global orientation to life, individuals with a strong SOC will have a general confidence that resources are available to meet the demands posed by stressful situations (Antonovsky, 1987).

This confidence increases the likelihood of positive coping expectancies. In related conceptual formulations (e.g. Bandura, 1986; Kobasa, 1979; Ursin, 1988) coping expectancies are assumed to moderate reactions to stress. In line with these models, Antonovsky (1987) proposes that a strong SOC may help to prevent stress from turning into potential harmful tension.

[The researcher therefore feels that the environment must remain constant in fitting with his individual needs thus supporting Bastian to achieve a continuum of environment as suggest by his analytical psychoanalyst.]

SOC and the mechanisms of health complaints

Low perceived control over stressful conditions have been associated with a general tonic activation involving all biological response systems, including changes in euro-endocrine, vegetative, neuro-muscular, central-nervous and immune system functioning (Ursin, 1997). Activation is sustained when coping efforts to remove the stressor are unsuccessful, or when no attempts are made to remove the stressor i.e. helplessness.

Sustained activation causes long term sensitisation of neural transmission (Antelman, Soares, & Gershon, 1997; Dubner & Ruda, 1992; Woolf & Thompson, 1991). Recent contributions view long-term sensitisation as a candidate mechanism for chronically elevated levels of health complaints (Ursin, 1997).

In summary, these above findings suggest that stressful appraisals, negative coping expectancies and unsuccessful coping behaviour are associated with physiological processes that may permanently lower the threshold for experiencing subjective health complaints.

SOC in adolescence

The hypothesised limited role for SOC in adolescent health, has been paralleled by a limited research focus on these groups. Some authors view adolescent experiences as important for the development of SOC in adulthood (e.g. Lundberg, 1997; Cederblad, Dahlin, Hagnell, & Hansson, 1994) but few contributions have addressed the potential health impact SOC may have during adolescence.

The few studies on child and adolescent SOC, have to a large degree focused on particular risk groups, such as adolescents experiencing evacuation stress (Antonovsky & Sagy, 1986), learning disabled children (Margalit & Efrati, 1996), and adolescents with chronic disease (Baker, 1998).

Contrary to the idea of a ‘fluid and weak’ adolescent SOC, these studies indicate that a ‘young’ SOC may contribute to stress and coping in much the same way as does the ‘mature’ adult SOC. School related demands are potent sources of stress in adolescent normal populations (Eme, Maisak, & Goodale, 1979; Greene, 1988; Henker, Whalen, & O’Neil, 1995).

Elevated levels of such stress are associated with psychological distress (Wagner & Compas, 1990; Ystgaard, 1997) and somatic complaints (Aro et al., 1987; Garralda, 1996; Hurrelmann et al., 1988).

[As schooling is mandatory in most countries, exposure to school demands is beyond the control of adolescents. Identification of resources that may help to prevent stressful appraisals, or moderate the adverse health impact of stress, may serve as an important first step in developing preventive strategies.]

Antonovsky’s (1987) original contribution suggests that the adolescent SOC may affect level of health complaints indirectly by preventing school-related stress appraisals, interactively by moderating the impact of stress, and directly by reducing the likelihood of sustained activation. **A potential shortcoming in previous research, is the failure to compare the relative importance of these mechanisms at given developmental stages in life**. To gain more knowledge on the role of SOC in early adolescents' adaptation to school-related stress, the paper investigated each of these assumed relationships:

1. SOC is inversely related to appraisals of school related stress
2. SOC moderates the relationship between school related stresses on subjective health complaints
3. SOC is inversely related to health complaints

The above paper was to assess the role of SOC in adolescent's health adaptation to school-related stress. The results provided some support for the general stress-health mechanisms that Antonovsky formulated. While the study did not address stability of SOC, the strong cross-sectional consistency across samples, indirectly point to a degree of stability in SOC in adolescence. As such the present study (2001) underscores the need to adopt a life-span perspective when examining the role of sense of coherence in health.

The cross-sectional design does not permit the author (Torbjorn et al.) to draw strong practical implications from the study, but the study does take a first step in providing a conceptual framework for how salutogenic factors may intervene on adolescent adaptation to school-related demands.

PAEDIATRICS AND CHILD HEALTH
PROMOTING CHILDREN'S EMOTIONAL WELLBEING

Corinne Rees

2010

Promotion of emotional wellbeing should be a priority integral to all paediatric practice. The emotional environment may determine or merely influence children's needs but is **always relevant**. The root of children's emotional state is the quality of their **parental attachments**, consideration of which should be routine.

Children's earliest experience of parental relationships determines their preconceptions of themselves and relationships, their foundations of verbal and non-verbal communication, and programming of the stress regulation system.

It has a life-long influence on physical and psychological wellbeing, and on growth, development and behaviour. Recognition of the overriding priority for children of adequate attachment should ensure that establishment of secure foundations is a priority of neonatology, and that it is at the core of safeguarding children and support of recovery from neglect and abuse.

Consideration of the psychological context of all paediatric problems, and seamless integration of paediatric and specialist mental health services, need to be achieved through training, practice and professional organisation. Recognition of the reality of iatrogenic psychological harm should ensure that efforts to prevent such, is as high a priority as avoidance of physical harm.

Promotion of emotional wellbeing should be a prominent consideration throughout paediatrics. This requires consideration of what emotional health means, why it matters, how it is achieved, and what one is aiming for, see [Table 1].

It means considering how both children's and parents' emotional states influence physical and psychological health, growth and development. The core of children's emotional wellbeing is the quality of their parental relationships, see [Table2].

Paediatricians must protect these and recognise and help to remedy poor attachment. As important as the current emotional environments are, the initial foundations, are on which subsequent experience builds, influencing physical and psychological health throughout the life-span and into the next generation. Children's brains develop according to use, moulding future function.

Mind and body are inextricably linked in every illness, trivial or otherwise; all necessarily behave, in illness as in health. Emotion affects everybody system. At all ages emotional wellbeing influences physical and psychological manifestations of stress: in infants it affects stress system programming with life-long implications.

Childhood emotional disadvantage is costly. It compromises childhood health and safe independence. It predisposes to common causes of adult morbidity and mortality, substance abuse, involvement in crime as victim and perpetrator, and parenting difficulty.

Good care means listening. It means standing back and noticing the emotional context of presenting problems. It always matters, the questions being how, and how much. It means realising that iatrogenic psychological harm happens, recognising knowledge gaps and shortcomings of practice and service structure, and keeping humility and empathy to the fore.

What is Emotional Wellbeing?

Emotional wellbeing is more readily recognised than defined (Table 1).

It is multifaceted, its interrelating elements on a spectrum from optimal to damaging. ***Self-esteem*** is at the core of its importance, and parental attachment of its origins.

Emotional wellbeing does not mean undiluted happiness and success. It is rather a state of emotional safety, of believing oneself to be unconditionally valued despite shortcomings, and worthy of this, and able to accept responsibility for one’s actions. It involves achieving healthy identity, effective independence and relationships, tolerating change without anxiety-fuelled over-control, and managing stress. It means balancing doubt and confidence, handling difficulty and enjoying success.

Normal Emotional Development

Emotional development e acquisition of psychological tools needed for adulthood e is like building a wall. Foundations remain important whatever is added. However, neuronal plasticity allows resilience, the more so the younger the child. The bottom bricks come through parental attachment, shaping the relationship-dependent right hemisphere (Table 2).

Stress Regulation

Infants depend on parents to regulate their stress, for which they must regulate their own. Their effectiveness contributes to programming the stress systems. Well-attuned parents provide predictable routine to reduce anxiety, adequate sleep, day-night differential, and freedom from excessive noise and disturbance.

Development and Emotional Wellbeing

Development is complexly linked to children's emotional environment - particularly to the quality of the close relationships, on which they depend for instruction, stimulation, opportunity, motivation, tools and conditions to learn, role model and motivation, see [Table 3]. Early experience is as important a consideration as current circumstances. Dysfunctional early attachment has multiple consequences for development: understanding these helps recognition of emotional abuse.

Behaviour

Behaviour serves a purpose and is determined by its anticipated effect. At the core of its purpose are usually attention and control, deriving from early experience of relationships. Children's behaviour indicates whether they perceive attention as helpful, reliable and predictable, and control as safely relinquished.

These perceptions determine their confidence in achieving and holding attention, the extent to which they seek and risk relinquishing it, and their tolerance of separation, physical and emotional [e.g. discipline]. If attention is craved, behaviour achieving it is learnt.

Behaviour is additionally coloured by perceptions of authority, 'normal' behaviour, and trust. It depends on ability to communicate verbally and non-verbally, and to regulate stress and emotion. It is influenced by fear of failure and rejection, inattention, hyperactivity and anxiety, intolerance of change, and fatigue.

However, it starts, behaviour is a two-way process, the reaction being as important as the child's intentions, an important consideration in management. When early foundations were dysfunctional, multiple strands typically interrelate, in vicious circles encompassing poor self-esteem.

ELEMENTS OF EMOTIONAL WELLBEING

Independent function

Self-Awareness
- Ability to differentiate and name emotions
- Recognition of personal strengths and limitations
- Sense of choice and control

Emotional Safety
- Good self-esteem
- Coherent narrative of life circumstances
- Secure identity
- Valued roles
- Success; challenge
- Feeling unconditionally valued

Executive Function
- Ability to learn from experience, plan
- Concentration

Good mental health

Functioning through relationships

Perception of relationships
- Differentiating close relationships from others
- Appropriate preconceptions of roles and responsibilities; trust

Use of Relationships

- Confidence in achieving and sustaining attention
- Ability to use relationships for friendship, intimacy, instruction, cooperation
- Ability to read relationships, negotiate, manage disagreement
- Ability to relinquish control
- Ability to adjust to different relationships

Communication

- Effective verbal and non-verbal communication
- Intuitive attunement; empathy

Functioning in the World

- Recognition of danger without excessive anxiety
- Concept of reality
- Ability to accept challenge and risk failure
- Adaptability
- Regulation of stress and emotion
- Tolerance of change and unpredictability
- Resilience
- Effective coping strategies

Table 1: Elements of well-being

FACETS OF GOOD EMOTIONAL CARE

Attachment
- Sensitive, predictable, timely parental attunement

Environment
- Adequate calm
- Age-appropriate material; varied experience; challenge

Structure
- Predictable routine and expectations; managing change
- Day-night routine; adequate sleep

Regulation
- Controlled risk without overprotection
- Role model for regulating stress [calming, exercise] and managing difficulty

Self-esteem
- Opportunity for success
- Praise outweighing criticism

Managing feelings
- Creativity; pretend play
- Naming and discussing feelings
- One-to-one time

Relationships
- Demonstration of appropriate roles, trust, personal boundaries, behaviour
- Teaching negotiation, reconciliation, apology, communication skills

Responsibility
- Encouraging age-appropriate responsibility
- Modelling taking responsibility for actions

Table 2: Facets of good emotional care

Safeguarding and recovery

Emotional wellbeing must be at the core of safeguarding decisions.

[As the researcher has previously stated, Bastian’s self-esteem is of a higher importance, as based on his early childhood experiences and parenting; therefore it is critical for him to have a continuum of his self-awareness so as to not afford him his own conflicting contradictions which in turn will affect his self-esteem.]

FACTORS LINKING EMOTION AND DEVELOPMENT

Ability to use Relationships to Learn

Assumptions: are the value, safety and predictability of relationships

***Avoidance*:** advanced non-people skills and self-help; delayed communication

***Anxiety*:** attention accelerates skills achieving attention

-Understanding of roles, hierarchy, authority; trust
-Ability to relinquish control
-Extent of desire to please
-Ability to share attention
-Effectiveness of verbal and non-verbal communication
-Understanding of expected behaviour

Individual function

-Fear of failure
-Executive function: learning from experience, planning, concentration
-Mental health
-Motivation, interest, mood
-Over-anxiety, fearlessness
-Stress regulation
-Tolerance of change
-Imagination: retreat to fantasy; hypervigilance generating acting skill

Opportunity
-Stimulation; varied experience
-School attendance; exclusion

Associations
-Intrauterine exposure to drugs, alcohol, violence, malnutrition
-Poor diet [e.g. iron, omegas oils]
-Pica

Table 3: Factors linking emotion and development

First, Do No Harm

Sources of iatrogenic psychological harm: Doctors are trained to recognize physical risk. Psychological harm is relatively overlooked, but often of greater and more sustained importance, and less reversible. Prevention means understanding how, when and why harm is likely. Harm comes from the ill-judged spoken word, and from professional attitude and behaviour.

It comes from failure to listen and from misassumption filling unrecognized gaps in professional knowledge. Paediatricians must recognise when they do not know and learn by detailed listening with a genuine sense of enquiry, and examination.

Harm comes from disregard of children’s capacity to understand adult communication, and from inadequately explained physical interventions. It comes from clumsy discussion of psychological factors through inadequate thought to precise meaning, and from poorly handled family relationships. It comes from disregard of the norms of adolescence, and unboundried empowerment. It comes from over-specialisation and, particularly, mind-body separation.

Maturation

In the mid-school years children face the emotional complexity of illness without the maturity to manage it. Self-esteem is compromised by ‘difference’, missed opportunity, social isolation, and sometimes self-blame. Adolescence becomes complex. Understanding its normal course and ambiguities is essential for safe professional practice, and to avoid being unwittingly drawn into roles which undermine parental relationships. Adolescents fluctuate ambivalently between dependency and independence, pushing against those on whom they depend most, attachment being the paradoxical key to safe separation.

Prevention

Prevention requires professional sensitivity, humility and self-reflection, testing the appropriateness to the specific child of preconceptions brought to assessment. It means seeing through children’s and parents’ eyes and **respecting their levels of understanding**. Listening matters: so does appearing to listen. Those who feel misunderstood may shout louder. Any inclination to override what is described must be fully justified, recognising the risk of so doing.

Protecting emotional wellbeing means recognising when psychological aetiology is there and when it is not. Psychological attribution needs to make sense. It is not a safe default, and needs supportive evidence, as physical attribution does.

Unexplained psychological attribution may seem close to ‘not real’, with hints of blame, causing young people serious confusion. Mental health services, when needed, should be positively presented, with clear purpose.

Conclusion

High quality paediatric care means standing back sufficiently to see the wider picture of relationships and emotional wellbeing surrounding each presenting problem. It means acknowledging the iatrogenic harm of ill-judged words and professional behaviour, taking as much care to avoid psychological as physical harm. It means making promotion of emotional wellbeing a priority through training, practice and service organisation, remembering the cost of failing to do so.

PROMOTING CHILDREN'S HEALTH

Paediatrics and child health

Blair

2010

The recently launched Healthy Child Programme in England and its equivalents in the UK provide a supportive framework on which to tailor health promoting activities. Qualities of an effective health promoting paediatrician include recognition of the wider social determinants of health, advocacy and leadership, the use of promotional interviewing techniques and opportunistic health education using a strength-based approach.

Promoting Children's Health sets out how paediatricians might be able to promote children's health as part of their day-to-day practice, as well as contributing to a larger programme of preventive health care. The first part describes a working definition of health promotion for children and their families, and then goes on to look at the framework which is in place for children in the UK as part of the refreshed Healthy Child Programme, launched in autumn 2009.

A number of key areas are described, including promotion of ***emotional health***, ***learning and literacy***, ***nutritional health***, ***injury prevention***, ***immunisation*** and ***healthy lifestyles***. Finally, the article describes the qualities required of health promoting paediatrician.

Definitions and frameworks

Definitions of health promotion vary depending on the level of focus; whether individual or societal. It can be defined as ''the process of enabling people to increase control over and to improve their health''. This is often achieved through a combination of health education and related organisation, political and economic programmes designed to support changes in behaviour, and changes in the environment that will improve health.

For example, the interventions used at an individual level would be 'health education' and 'individual empowerment', at the social and community level; 'social action' and 'empowerment of the local community', and at government level, lobbying and advocacy directed at healthy public policy.

'Health education' is probably the activity which clinicians feel most familiar with. The outcome desired is one of an increase in health literacy or as Nutbeam describes ''cognitive and social skills which determine the motivation and ability of an individual to gain access to and understanding use of information in ways that promote health.''

The umbrella framework used in England for promoting health in children is the Healthy Child Programme (HCP). The programme starts antenatally and covers both the early preschool years and later school years up until the age of 19 years, or *latterly 25 years as part of the (EHCP – 2014). It combines a number of different activities including screening, immunisation, early detection and treatment of illness and developmental impairments, health promotion and parenting support.

The programme is key to delivering the 2008 to 2011 Public Service Agreements (PSAs) for improving the health and well-being of children. It makes a crucial contribution to Every Child Matters outcomes as well as to the National Service Framework Children, Young People and Maternity Services.

The PCH programme has a strong emphasis on parenting support, takes into account the rapid scientific advances around the neurobiological development of children in the early years, particularly stressing the importance of attachment and ***positive parenting*** in the first few years of life.

Emotional health and wellbeing

Probably the most important determinant of a child’s health is the health and education of their parents. The ***immediate social*** and ***emotional environment*** will determine how the emerging brain develops in terms of its responsiveness to outside influences. For the *older school child*, *peer group becomes particularly influential, as does the environment within the school*. Bullying is a major issue for many children and is reported as one of the most common fears for school-age children in the UK. Indeed, the rates of bullying are amongst the highest in Europe. (Blair, 2010)

Health inequalities - a cross cutting theme

There are many reasons for health inequalities including the long-term effects of a disadvantaged social position, differences in access to information, (services and resources), differences in exposure to risk, a sense of lack of control of one’s own life circumstances, a healthcare system that may reinforce ***social*** and ***economic inequalities***. Many of these factors will affect people’s ability to withstand the biological, social psychological and economic stressors that often trigger ill-health. The same factors will affect the capacity to change behaviour.

The health promoting paediatrician

What makes a health promoting paediatrician? What are the key competencies required?

> **Professionals must recognition of the holistic nature of children’s health issues, and a deeper understanding of the bio-psychosocial**

determinants of their health status. In addition, a careful ear during the consultation to pick up on cues which might explore issues where further behavioural change might be encouraged.

Conclusion

Paediatricians and all other child intervention specialists are in an influential position to reinforce key health promotion themes as part of a national programme, both in their individual practice, the hospital and the community as a whole.

EMOTIONAL WELLBEING AND MENTAL HEALTH: AN EXPLORATION INTO HEALTH PROMOTION IN YOUNG PEOPLE AND FAMILIES

Coverdale

2015

Promoting Mental Health and Emotional Wellbeing (EWB) in children and young people (YP) is vitally important for their psycho-social development. Critical review of the literature reveals a dearth of research that has explored the perspective of the child, adolescent or adult in this concept, with much research being intervention focused and promoted at **crisis level**. The above study aimed to address this gap in understanding of young persons' and parents' perspectives.

Study participants identified key constructs for good EWB as stability, coping ability, happiness, confidence, balance, empathy and being grounded. Feeling comfortable with self, managing and controlling emotions and having the confidence to persevere with challenges were all felt to contribute to a positive sense of EWB.

Sources of support were overwhelmingly cited as family and friends, with ***schools identified as a potentially good environment*** for supporting and promoting the EWB of pupils. Participants stressed the need for a positive attitude change towards YP, advocating this as promoting a sense of belonging and community citizenship. A lay-informed 'recipe' for successful EWB promotion is drawn out, centred on the core goal of raising awareness and understanding of YP's EWB, in the YP themselves, their parents, schools and the wider community.

Conclusions: The research provided key messages for society, policy makers, education and public health and healthcare practitioners for integration into the delivery of services for YP and families that include education on supporting EWB, activities for YP and a multi-agency approach to supporting families within the community.

The last two decades have seen a growing body of seminal work exploring emotional and mental health and wellbeing, but a dearth of good quality research and evaluations on promoting emotional wellbeing (EWB) in young people (YP) in the United Kingdom is still lacking. There still remains a lack of agreement over its definition. EWB is defined by the World Health Organization (WHO) as a state of wellbeing in which the individual realises their own abilities, can cope with the normal stresses of life, work productively and fruitfully and is able to make a contribution to the community.

The Health Development Agency (HAD) further argues that EWB is 'a holistic, subjective state which is present when a range of feelings, among them; energy, confidence, openness, enjoyment, happiness, calmness and caring, are combined and balanced'.

Policy and research literature acknowledged varying aspects of EWB. For example, the National Institute for Health and Care Excellence (NICE), stated in their policy guidance that promoting YP's social and EWB encompasses:

- *Psychological wellbeing/good mental health* – the feeling of autonomy and control over one's life, problem solving skills, resilience, attentiveness and a sense of involvement with others.

- *Social wellbeing* – the ability to have good relationships with others and to avoid disruptive behaviour, delinquency, violence or bullying.

- *EWB* – happiness, confidence and not feeling depressed.

Adi *et al*. argue that psychological wellbeing involves having self-efficacy, itself comprising high self-esteem, power and control, confidence and positive beliefs about the ability to change a situation and succeed. Uskul and Greenglass suggested that psychological wellbeing involves an absence of depression, a high life satisfaction, coping capacity and optimism; good psychological wellbeing becomes a sound indicator of how someone will cope in a stressful situation. Thus, EWB is both separate from mental (ill) health and comprises good mental health within its scope. As Rees argues within the context of clinical paediatric care, EWB is recognised rather than defined precisely; moreover, as in the NICE definition above, it is multi-faceted, with its interrelating elements being on a spectrum from optimum to damaging.

[Much of the existing research on EWB is North American or Australasia based, intervention focused and promoted at crisis level, for example, addressing low self-esteem, self-harm and attempted suicide. Moreover, the meaning of EWB is largely professionally defined, with limited insight into the views of YP or parents of YP, despite a plethora of information on the health and wellbeing needs of pre-adolescent young children, with advocacy for a concentration of resources in the early years.]

The limited parental research has focused on parenting in small children or parental management of vulnerable children and YP, with little insight provided into factors that are important in the development of EWB. Parenting is a multiplex concept, with cultural and social contextualisation influencing the type of parenting and the success of parenting. However, picking up the skills and knowledge on how to be a 'good enough parent' is extremely ad hoc. However, it is well recognised that relationships within families is a key influencing factor on good emotional health and wellbeing.

Coverdale's article shares the findings of a study that aimed to address the gap in the evidence base, of hearing the voices of YP and those of parents of YP and gaining insight into their perceptions about EWB and factors that may promote and protect it.

The meaning of EWB to YP and parents of YP Both YP and parents of YP described feelings of EWB as being on a continuum from very poor to very good and that it was okay to feel that range of emotions. Both groups discussed stability, happiness, an ability to cope, being confident and comfortable with 'who you are' and 'where you fit in' and being empathic as being key to good EWB. Being able to enjoy life was also acknowledged as subjective and dependent upon what was happening in their lives and not a fixed state.

For YP, stability was linked to coping, confidence, empathy and being able to control and manage their range of emotions. For parents, stability was perceived to be more likely in a YP who was balanced, grounded, able to cope, resilient, able to take risks, deal with challenges and manage their emotions.

[The researcher, finds, that were Bastian (or any other child with complex neurodivergent conditions) placed in an oppugning environment, they would end up being stripped of managing his/her/their emotions and therefore would be encouraged by default in following a pattern of feared behaviour. This is backed up by the increasing SENDist Educational Tribunal statistics.**]**

Both YP and parents discussed the importance of being able to rationalise and manage the fluctuation of emotions, without allowing their response to these emotions to be extreme. Achieving and being successful was important, with both YP and parents mentioning Maslow's hierarchy of needs when discussing accomplishment and self-actualisation.

For both YP and parents, feeling confident and comfortable with self was perceived as a key component of good EWB. For YP, this also influenced their management of expectations, along with their perception of life's challenges.

[Bastian as well as other neurodivergent children instinctively know where they feel comfortable, it's instinctive; therefore it is a perquisite for any SEND child to be able to choose their own environments and or schooling institution, based on how they feel.]

Parents felt it helped YP to communicate their feelings and to problem solve. Empathy was seen by both YP and parents to be a positive aspect of EWB and being able to understand other people's emotions as well as their own. Parents expressed their pride when their YP showed empathy with and for others.

YP and parents of YP discussed the importance of good citizenship and a need for a cultural change in societal attitudes towards YP. Parents recognised that the engendering of respect was something that needed addressing between YP and the older generation, citing; seeking opportunities to meet together socially and undertaking voluntary work as a way forward. Parents wanted services that would provide early and non-stigmatising help and support for YP, such as advice or drop-in sessions within the community.

Meaning of EWB to YP and Parents:

- Being stable and able to cope
- Being comfortable with self
- Having empathy for others
- Being successful
- On a continuum

PERSPECTIVES		
Theme / Concept	YP Quotes	Parent Quotes
Education	*‘Emotional education such as being self-aware, being able to self-analyse and accept feelings can be good/bad’*	‘*I would like teachers to have education and training in promoting and supporting confidence and self-esteem in teenagers*’
	‘*Teachers having education and training on managing children and YP’s emotional wellbeing and mental health issues such as bullying, poor self-esteem … being able to identify those kids who are struggling early on*’	‘*Fostering a caring culture*’
	‘*I don’t know what is included in their education but teaching them about bullying, abuse*’	‘*Group work with YP … an understanding of what other people have to go through*’
	‘*Start giving those tools to people from a young age in order to process how they feel*’	*‘If you have a culture of caring and being quite tough on any sort of bullying or alienation type behaviour … it keeps it under control’*
Addressing perceived stigma surrounding seeking support		‘*Parenting class sounds like school and you go to school to be taught things … you’re not a good enough parent*’
	‘*The name of the group, if the name is something like Depression Society*’	‘*Advice services that do not have a negative label … youth workers that have experience and can give advice that are not seen as stigmatising if you go to see them*’
	‘*I think we need to get over the fact that you are going to visit … not being ashamed … advertising not to be embarrassed, to admit there’s something wrong and they need support … It’s to do with confidence … confidentiality*’	

An indicative lay-formed recipe for successful promotion of EWB:

- Raise awareness of EWB among teachers and YP and Educational Psychologists
- To support and enable learning discussions about emotional issues

- Develop parents own understanding about YP’s EWB
- Reduce stigma to discussing EWB by YP and parents
- To promote discussion of EWB issues between YP
- To promote discussion of EWB of the YP and their parents
- Reduce stigma about access and raise awareness of help and advice services to YP in schools and the community
- To enable its easier access
- To enable early access to its services
- Change attitudes in the community and society in general to YP
- To create a more positive attitude to YP and enable and value their engagement in community activities
- To enhance a YP’s sense of belonging in the community

The findings of this study portray a lay perspective of the meaning of EWB and give an insight into the support participants would value to promote YP’s EWB. While recognising the exploratory and small-scale nature of the study, the findings provide rich and deep insight into a lay view grounded in the views of YP and parents of YP. These both cohere with and add to existing knowledge in the area and provide pointers towards a recipe for the successful promotion of EWB in YP.

Overlapping concepts between this study’s participants and previous empirical studies with YP are evident, such as being empathic, achieving, coping and being optimistic. Little difference is apparent between the overall definitions of parents and YP and existing professional expositions.

Additional aspects were however raised as, the YP emphasised EWB as being subjective, changeable and dependent on day-to-day issues, and thus perceptions of success were personal. Parents talked about their own YP being able to communicate their emotions and feelings, this being seen as a sign of good EWB, along with being grounded and on an even keel, as symbols of stability in their YP.

The parental findings provided new insight into the impact on parents of their own YP’s EWB. Areas mentioned included the impact of their ***YP’s mood, their relationships with friends and their behaviour, both at home and at school, one parent depicting these as ‘absorbing their emotions***.

A number of other areas of valued support were emphasised, all adding to anowledge in the area. First, an important role was suggested for services such as drop-ins and peer mentorship within the ***community or school setting***.

Second, schools were seen as a potential source of support, with both YP and parents calling for formal education for parents and YP on EWB. YP also suggested that education about emotional health issues should become part of teacher-training programmes; this, they felt, would enable the normalisation of discussions about

EWB and encourage earlier help seeking. One perhaps surprising omission in the findings was study participants' general disregard for the role and potential of health services, as currently provided.

Healthcare services were seen as illness services and not a place to go for emotional support 'when you are emotionally wobbly'. Both parents and YP reported not knowing where to go for help. They pointed to the need for effective and sensitive marketing of services, to promote awareness and reduce potential stigma about their use. This has potentially important implications for policy and practice.

The above articles aim was to highlight EWB and to promote recognition of the normality of YP experiencing and expressing stress, anxiety, unhappiness and relationship problems. The provision of places to 'hang-out' and promotion of intergenerational activities might also promote a sense of community citizenship, 'fitting in' being seen as vital for YP's EWB.

Conclusion

The findings of this small-scale qualitative research study have begun to identify lay perspectives on YP's EWB and outline a lay-informed recipe for successful promotion of EWB in YP, to inform policy and practice. Participants identified a range of important factors that if acted upon in practice would provide an opportunity for younger children and YP to benefit in the future.

Given the criticality of YP's EWB, exploring the precursors to mental ill health is important, and to identify ways to enhance strong EWB and thus to prevent mental and other social adjustment problems is critical and a must. Further research is needed on YP and parents of YP to enable the development of acceptable strategies to support the development of successful EWB.

[The researcher finds that the above article on EWB is the most current appropriate research to date (2017), which highlights the necessity for EWB interventions. This is reflected in a statement as articulated by Bastian Willicott, a YP: "*I know how to handle me, but put me in the wrong environment, and I feel stuck, feared and unworthy of being all that I can be. I don't want to become ill; I don't want to feel awkward; I just want to be allowed a choice. I know what environment I feel happier in, but the professional people just ignore me. I am so angry, upset and hurt; that I feel it's best if I just hide away."***]**

INTERRELATIONSHIPS BETWEEN COPING, SCHOOL CONNECTEDNESS AND WELLBEING

Frydenberg, el al.

2009

This study examined the interrelationships between coping styles, emotional wellbeing, and school connectedness using path analysis. A total of 536 Year 8 students (241 boys and 295 girls) responded to an in-class survey and the *Adolescent Coping Scale* (Frydenberg & Lewis, 1993a) as part of a larger study.

Productive coping styles were positively related to both student-reported sense of wellbeing and, to a lesser extent, to school connectedness. A non-productive coping style was found to be inversely related to students' sense of wellbeing and connection to school. Students' sense of emotional wellbeing was found to be positively related to school connectedness.

[The researcher has highlighted School Connectedness by virtue of Bastian's primary school placement/setting; as they created a strong, centred EWB child.]

The negative relationships between non-productive coping with emotional wellbeing and, to a lesser extent, with school connectedness highlight the importance of taking into account the influence of risk factors as well as positive factors when focusing on enhancement of wellbeing and connectedness in secondary school students.

The growing interest in students' connectedness to school as a key influence on educational outcomes coincides with the emergence of middle years of schooling (Years 5–9) as an educational priority across Australia. (for example, Cole, Mahar & Vindurampulle, 2006)

The years spanning early adolescence (ages 10–15) are generally understood to represent a critical stage of adolescent development (Barratt, 1998).The rapid physical, cognitive and social changes, and often new and increased expectations at school (Eccles & Midgley, 1990) are demands that have the potential for overloading the adjustment ability of the young person (Feldman, Rubenstein & Rubin, 1988).

[Therefore, keeping a continuum of environment, in children with (LD) is critical, so as to enhance a stable EWB.]

Australian research has indicated that it is during these middle years of schooling that the highest incidence of disengagement, boredom, alienation, disruptive behaviour and disenchantment occur (Cumming & Cormack, 1996; Hill & Rowe, 1998). Understanding the factors relating to school connectedness in the middle years may help education leaders and school practitioners, (Educational Psychologists/Local Authorities) to design more effective school environments, as well as to ***listen*** to the child/YP and Parents alike.

The two factors associated with adaptation in early adolescence, coping and emotional wellbeing, are investigated here, to identify the way in which they may be related to school connectedness.

Background

Coping

In order to navigate through life successfully and to deal adequately with stress, individuals must learn to deal effectively with problems. Problem-solving, is an important coping skill, is essential as effective problem-solving has been shown to moderate the effects of stress (Printz, Shermis & Webb, 1999). While an individual's ability to deal with problems is influenced largely by individual characteristics such as life experience and personality, much can be done to maximise coping abilities.

Coping is typically referred to as the cognitive and affective responses used by an individual to deal with problems encountered in everyday life. More formally, coping is defined as 'the ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus, 1993, p. 237). Individuals generally refer to a certain repertoire of coping strategies when faced with stressful events. The choice of these strategies can be influenced by the situational context of the stressor.

[Bastian and other LD children prefer, less taxing environments, so when placed in over taxing / over stimulating environments/school settings, that deal with moderate to severe complex behaviours and or where students display unpredicted behaviours, it allows for the (LD) child to suffer great anxieties and or withdrawal symptoms, which in turn leads to school avoidance, children need to feel they can cope, and not be forced to cope. Forcing a child to cope in an ill-suited environment is counterproductive.]

Adolescents are likely to face a range of acute and chronic stressors as well as daily hassles in their lives, such as those relating to family, school and peers. While it is not possible to eradicate these stressors, their severity can be reduced. Where a stressful situation is amenable to change, adolescents appear more likely to use problem-solving strategies. In contrast, emotion-related strategies, such as worry or self-blame, are more likely to be used in situations appraised as unchangeable (Folkman & Lazarus, 1980). Compas, Malcarne and Fondacaro (1988) asserted that adolescents assess academic stressors as more controllable.

Both local and international studies have shown that the use of non-productive strategies such as self-blame, worry, keeping to self and wishful thinking have been linked with a number of adverse outcomes in young people including depression (Cunningham & Walker, 1999; Murberg & Bru, 2005; Seiffge-Krenke & Klessinger, 2000). In comparison, productive coping strategies such as **solving the problem**, working hard and **relaxing** have been associated with better health outcomes (Frydenberg & Lewis, 1999).

Wellbeing

To deal adaptively with the physical, intellectual and social changes required in early adolescence, a positive state of emotional wellbeing is deemed necessary. Coping with social and situational causes of stress impacts specifically on an individual's subjective wellbeing and self-efficacy, and more broadly affects relationships, aspirations and academic performance (Greenglass, 2002).

In the past, the discussion of wellbeing has often been framed within a deficit model (Fraillon, 2004). There is a growing trend to reframe notions of wellbeing to incorporate more positive states of being.

Within this paradigm, the focus tends to be on general indicators of wellbeing such as health, resilience, *self-concept*, *self-efficacy* and *achievement*. Positive indicators of emotional wellbeing may include *being able to express a point of view*, having friends to talk to who can be trusted, being valued by others, and *feeling safe from harm*.

In a sample of British adolescents, Bergmann and Scott (2001) identified a marked gender difference in wellbeing: girls reported lower self-esteem, higher negative self-efficacy and unhappiness, and more frequent experiences of worry compared with boys. Additionally, these gender differences have been reflected both in the use of avoidant coping strategies such as wishful thinking or immersing oneself in other preoccupations, and in physical and psychological health symptoms, such as anger, depression and negative mood (Wilson et al., 2005).

School connectedness

As with the concept of wellbeing, school connectedness has been studied under various names with a variety of definitions (Blum & Libbey, 2004). Examples of terms used include 'school belonging' (Osterman, 2000; Willms, 2003), 'student engagement' (Taylor & Nelms, 2006), 'school bonding' (Catalano et al., 2004), and 'teacher support' (Klem & Connell, 2004; Reddy, Rhodes & Mulhall, 2003).

'Bastian: "I don't belong at Oak Lodge; I just don't fit in."'

Libbey (2004) reviewed studies that are designed to measure students' relationships to their schools. She found the definitions of the construct appeared to vary based on the indicators used, which included students' attitude and motivation toward school and learning, the degree to which students felt they were liked by others at school, and students' commitment, involvement and belief in school rules. For the purpose of the above study, school connectedness was defined as students' perceptions of being accepted by the school and identifying themselves as being part of the school.

Previous studies have shown strong relationships between school connectedness and students' academic and psychological outcomes (see Bond et al., 2007; McGraw et al., 2008; McNeely & Falci, 2004; Nutbeam et al., 1993; Resnick et al., 1997; Shochet et al., 2006). School connectedness has been found to be related to low levels of health-compromising behaviour, such as substance abuse (Carter et al, 2007).

One Australian study examined the associations between adolescent students' social relationships, mental health, substance use, school engagement, and school achievement. Students who only had good peer relationships, but poor school connectedness were at a greater risk of anxiety or depressive symptoms and substance abuse (Bond et al., 2007). In a one-year longitudinal Australian study of around 2000 early adolescent students, poor school connectedness was found to be a predictor of future mental health problems (Shochet et al., 2006).

The findings from these studies highlighted the importance of school connectedness for students' psychological wellbeing and academic achievement while they were at school and beyond.

The National Longitudinal Study of Adolescent Health in the USA (90 118 subjects) found an individual student's sense of school belonging was inversely related to depression, social rejection and school problems. When the data were aggregated at school level, belonging was positively related to greater reports of social rejection and school problems, and to higher-grade point averages.

The researchers (Frydenberg et al.) suggested that the results might imply that schools where most students felt that they belonged performed better academically. At the same time, those students who did not find themselves belonging to the school, felt a greater sense of rejection and therefore reported more school problems (Anderman, 2002).

An understanding of the relationships between school connectedness and students' coping behaviour may help to devise better school interventions, so as to improve students' psychological wellbeing as well as Local Authority Policy.

Student engagement is one of the terms that has been used interchangeably with school connectedness. This definition is similar to Jenkins's (1997) reference to school bonding. Regardless of differences in terminology, some clear findings have been established. As Resnick and colleagues (1997) demonstrated in their study of 12 118 adolescents from 80 high schools in the USA, school and parent connectedness are key factors in resiliency.

Interrelationships between coping, wellbeing and school connectedness

The authors (Frydenberg et al.) have not found studies that examine the interrelationships between coping, wellbeing and school connectedness. Studies generally indicate positive bivariate relationships between productive coping strategies and a sense of wellbeing (for example, Freedenberg & Lewis, 2009), wellbeing and school connectedness (for example, Carter et al., 2007), and positive coping and school connectedness, in the form of positive relationships with teachers.

Within the field of wellbeing research, there have been a number of studies (see Braun-Lewensohn et al., 2009; Heubeck & Neill, 1999) that investigated facets of wellbeing using the *Adolescent Coping Scale* (Frydenberg & Lewis, 1993a).

Furthermore, there is increasing evidence that students who report more frequent productive coping behaviour appear to have a better sense of emotional wellbeing (Frydenberg & Lewis, 2009).

Jenkin (1997) found that the best predictors for distinguishing between high and low self-efficacy were three coping strategies. These were focusing on the positive, solving the problem and working hard to achieve said.

In Australia, Patton and colleagues (1997) found that a low level of emotional wellbeing in adolescence was a risk factor for major depression, substance abuse and self-harm behaviour. Another study of wellbeing compared young people aged 12–18 years characterised by behavioural, psychological and physical problems with a group of healthy adolescents (Ebata & Moos, 1991).

The study measured use of both active and passive coping styles and used perceived happiness and self-worth as measures of wellbeing. Results demonstrated a link between greater use of active coping (positive appraisal, guidance or support or both, problem-solving) and higher levels of wellbeing.

The 'broader mind-set' with a positive mood state encourages exploration, extension of self and the sharing of information. Other studies have investigated the relationships between wellbeing, coping and academic achievement (Noto, 1995; Parsons, Frydenberg & Poole, 1996; Skinner & Wellborn, 1997).

[It is always in the best interest of any child to further their learning through positive structures than to solve the regression from failed environments. It is far easier to intervene in a child's life, than it is to 'fix' and or to seek to resolve the damages the adult lives with.]

Research findings generally indicated positive relationships between academic achievement and coping.

It has been recognised that students who feel connected to their school report fewer depressive symptoms (Shochet et al., 2006). This leads to an assumption about the likelihood of a positive relationship between school connectedness and wellbeing. Additionally, there are indications that adolescents are less likely to report a sense of wellbeing when they report use of negative coping strategies (Frydenberg & Lewis, 2002; 2009).

[Bastian has stated and highlighted the entire why's and wherefores, including stating what makes him, him. He has not been influenced by professionals, nor has he been influenced by his mother. The research of school placements was undertaken with Bastian in tow, the process was child centred and child led. Bastian was given a voice. Bastian's parent (Mother) and independent professionals, all complied with the CRC (Convention on the Rights of the Child) and allowed Bastian his voice, however, the Government, Local Authority and SENDist Judiciary, have failed Bastian, simply by not acknowledging their polices, laws and regulations, including using the ratified CRC Convention; Bastian's voice has been lost to the grave of politics where the tombstone reads – Did not pass the Best Use of Resource Test.]

Research aim

In summary, the literature that is available to date on wellbeing, coping and school connectedness appears to indicate that the relationship between each of these constructs could provide insights that may facilitate healthy adaptation. The aim of this study was to examine the contribution of productive and non-productive coping behaviour to both emotional wellbeing and school connectedness.

It is expected that the major impact on emotional wellbeing will be through greater use of productive coping and lesser use of non-productive coping. Since school connectedness is likely to be influenced by a range of factors (for example, **school climate (environment)**, and educational progress, and peer and teacher relationships), increasing productive coping and thus emotional wellbeing is not in itself likely to be sufficient but could be beneficial.

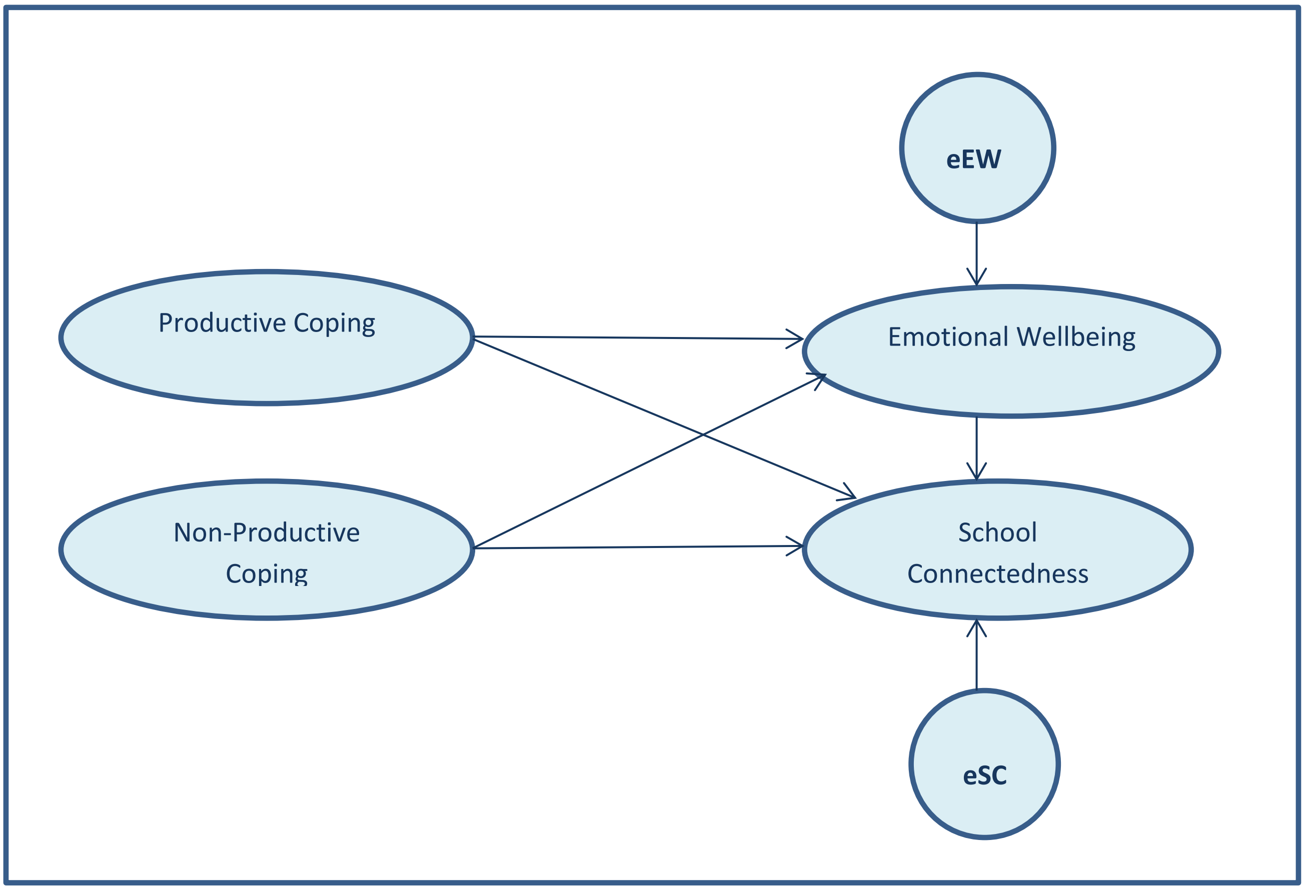


Figure 1 The hypothesised structural equation model of school connectedness with productive and non-productive coping styles and emotional wellbeing

Coping styles

Coping style was assessed using the *Adolescent Coping Scale–Short Form* (Frydenberg & Lewis, 1993), in which participants were asked to indicate what they generally do and what they did and feel when they experienced a stressful event.

Items contributing to the emotional wellbeing and school connectedness scales:

For the purposes of this report the researcher will highlight School connectedness items, Productive coping items and Non-Productive coping items.

School Connectedness Items

I feel comfortable with others in this school
I think that I 'fit in' at this school

Productive Coping Items

Look on the bright side of things and think of all that is good at this school

Non-Productive Coping Items

Worry about what will happen to me
Shut myself off from the problem so that I can avoid it
Don’t let others know how I am feeling

Discussion

The results of this study supported the hypothesised interrelationships between coping styles, emotional wellbeing, and school connectedness. Students who use more productive coping strategies had a better sense of wellbeing and reported greater connectedness with their school. The negative associations of non-productive coping with wellbeing and with connectedness tend to support the findings of Shochet et al. (2006) who showed that poor school connectedness predicts depressive symptoms in adolescents and depressive symptoms have been found to be associated with the use of non-productive coping strategies.

This study’s results indicated that students who reported a higher usage of non-productive coping strategies had a lower sense of wellbeing and school connectedness, although these relationships were less strong than those associated with productive coping. Wellbeing’s positive relationship with productive coping and inverse relationship with non-productive coping are consistent with Frydenberg and Lewis’ (2009) study of active and negative avoidant coping styles.

[This study correlates to that of Mark Carter’s neuropsychology report on Bastian, and how important it is to keep a continuum of environment.]

IMPORTANTCE OF WELLBEING: HEALTH – SCHOOL/EDUCATION POSOTION
[Mental and Emotional Health]

SOCIAL DEVELOPMENT GOALS
2016

1. **Ensure Healthy Lives and Promote well-being for all ages**

   By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote *mental health* and *well-being*.

2. **Ensure inclusive and equitable education and promote life-long learning opportunity for all**

   By 2030, ensure that all learners acquire the knowledge and skills needed to promote sustainable development, including, among others, through education for sustainable development and sustainable lifestyles, human rights, gender equality, promotion of a culture of peace and non-violence, global citizenship and appreciation of cultural diversity and of culture's contribution to sustainable development.

   Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all.

   [When the UK uses(PAM) Political Austerity Measures as a means to redress/cut 'policy' spending, – where does that leave them, in terms of moral positioning and human rights, when including the rare disabled or any disabled in matters of choice?]

   [The Cost Benefit Model statically highlights that preventative measures are more beneficial and more cost effective and carry a long term saving, than that of the current spending format which is 'Short Term Vision' or throwing millions of pounds down the judicial road, so as to stop any disabled child reaching their true potential.

   This short-term vision model to save money, is costing the government more, as the only 'party' that benefits from the financial stream, are Solicitors. The Government loses, Local Authorities lose, Schools lose, NHS Services lose, the families lose, and more importantly the child loses, with their futures disregarded.

The Disabled or Neurodivergent community should not have to fight for their rights, as they are already living with absolute and or relative suffering.

The UK Government will spend millions to stop any precedent decision from being ruled, yet, what the UK can't/won't understand, is that legislation needs to be evolutive and holistic, so as to take into the account the needs of its diverse population. Currently the only evolutive 'working documents' that take into account diverse population spectrums are The Convention on the Rights of the Child, The Universal Declaration of Human Rights and The European Convention on Human Rights.**]**

3. **Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective accountable and inclusive institutions at all levels**

   Promote the rule of law at the national and international levels and ensure equal access to justice for all.

   Ensure responsive, inclusive, participatory and representative decision-making at all levels.

   Ensure public access to information and protect fundamental freedoms, in accordance with national legislation and international agreements.

   Promote and enforce non-discriminatory laws and policies for sustainable development.

   [Who takes accountability when the Government fails? What happens when the Judiciary and Local Authorities fail to understand or interpret their own legislation and their own policies?]

EMOTIONAL WELLBEING AND ITS RELATION TO HEALTH
Physical disease may well result from emotional distress
Stewart-Brown

1998

In 1947 the World Health Organisation defined health as “a state of complete physical, mental and social wellbeing.” Until now the NHS (National Health Service – UK) has given precedence to promoting physical wellbeing, but the green paper ‘*Our Healthier Nation’* signals that this may need to change.

These statements are supported by an increasing body of epidemiological, social science, and experimental research that is beginning to suggest that initiatives which aim to promote physical wellbeing to the exclusion of mental and social wellbeing may be doomed to failure.

The concept of mental and social well-being is less well defined than that of physical wellbeing. Debate still continues about the meaning of the term mental health. A recent study in Scotland showed that lay people were more comfortable with the terms psychological and emotional wellbeing because they equated the term ‘mental health with mental illnesses. The concepts of social wellbeing and social disease (misuse of alcohol and drugs, domestic violence, child abuse) and the extent to which they are also the responsibility of the NHS, which can be seen as another controversial issue.

Nevertheless, some research shows that emotional distress creates susceptibility to physical illness. Exam stress increases susceptibility to viral infection, and stress from lack of control in the workplace or from life events creates susceptibility to cardiovascular disease. Animal studies reviewed by Wilkinson and Brunner (1994-1996) provide supporting evidence that emotional distress can lead to physical illness by affecting the immune response.

Solutions to apparently intractable public health problems like inequalities in health and unhealthy life-styles may therefore lie in research into *emotional wellbeing*. A broad range of studies is needed to test the hypothesis that emotional distress creates susceptibility to physical illness and a further range is to research interventions which can prevent emotional distress and promote mental and social health.

[It is the researcher’s positionality, and or hypothesis, that lays claim to the above, that emotional distress does create and lead to physical illness and mental health issues. This has been documented by NHS England and the researcher’s own (GP/Clinician) as well as Bastian’s clinical psychoanalyst. The stressors of appealing an education placement setting, created an abhorrent and avoidable judicial process, which saw the researcher having to endure a near cardiac arrest and mental health breakdown for the following:

1) 1 x Magistrates Court Trial - Accused of abusing Bastian's Public Funded Disability Allowances, for Bastian's care allowance whilst being a mature student. The Local Authority failed to check documentation pertaining to Bastian's allowance, judiciary ruled that all documents and declarations were filed, and held on record with the LA. – **Not Guilty (LA, failed to thoroughly investigate declarations.) [Threatened 5-year sentence and £20 000 fine]** (2014)

2) 1 x Educational Tribunal via SENDist, appealing Part 4 [Placement] – **Appeal Withheld (SENDist ruled in favour of the LA, by using legislation - 'Not best use of Public Resource' – despite the placement 'costed' out as being 'cost neutral' to the public's purse.)** (2014)

3) 1 x Magistrates Court Trial - Accused of failing to comply with an unlawful (SAO) School Attendance Order, despite the defendant being within the law to lawfully and legally home educate. – **Not Guilty (LA, failed to comply with legislation, failed to understand the law, and ruled that the LA had committed a State Crime, withdrew before ruling.) [Threatened 3 to 6 months sentence and £10 000 fine]** (2014-2016)

4) 1 x High Court Application in submission for Judicial Review, based on the SENDist Tribunal Decision. – **Application Withheld (High Court and Barristers Chambers ruled that it would not a yield an effective remedy based on the time scale of litigation, and best use of public resources, as the High Court costs would be higher than that of the schooling placement.)** (2015)

5) 1 x Magistrates Court Trial - Accused of failing to comply with an unlawful (SAO) School Attendance Order, despite the LA knowing they were committing a further State Crime. – **(LA, failed to comply with legislation, failed to understand the law, and ruled that the LA had committed a State Crime, withdrew before ruling.) [Threatened 3 to 6 months sentence and £10 000 fine] Local Authority Conceded** (2016)

6) 1 x European Court of Human Rights submission – seeking resolve for UK Human Rights Educational failings. – **Application / Trial Process heard by EC Chambers, it was ruled that before the case could be heard at Grand Chamber Tier, the UK must comply with the Child Rights Charter and an application to High Court must be allowed, it was further recommended that a combined Discrimination, Inclusion,**

Rare Disease Strategy and Damages application be filed simultaneously. (2016)

7) 1 x Educational Tribunal via SENDist, appealing Part 4 [Placement] – **Appeal Withheld (SENDist ruled in favour of the LA, by using legislation - 'Not best use of Public Resource' – despite the placement costed as being 'cost neutral' to the public's purse.)**

8) *1 x County Court → High Court Submission (Tort/Negligence for Damages) using legislated regulations pertaining to Disability Discrimination Act, Child Rights Act, Child and Families Act, Disability and Inclusion Act, Equality Act, Rare Disease Strategy, Human Rights Act and Child Rights Charter. (Pending Mid 2017)

9) *1 x Supreme Court Submission depending on outcome of County/High Court Ruling. (Pending - 2018)

10) *1 x ECHR (Grand Chamber) Submission for ruling against the UK – depending on our come of Supreme Court. (Pending - 2019)

11) *1 x United Nations Hearing Submission for recommendations to UK. (Pending - 2019)

[This is what survival looks like on paper – Janet Willicott – Not Guilty – The Above processes are because I have a disabled child, who needs an education - I live in the United Kingdom - The year is 2017.]

The researcher states: It is imperative that further research be carried out so as to avoid continued emotional distress, so as to promote effective mental health.

Two of the most promising approaches depend on a further body of research which shows that unresolved emotional distress in childhood is an important cause of emotional distress in adulthood. These approaches are parenting programmes and mental health promotion programmes in schools.

Several school mental health promotion programmes have been subject to controlled trials which showed a positive impact on emotional wellbeing. Through developing empathy and respect, both types of programmes improve self-esteem in children and parents and increased their ability to give and receive social and emotional support. Long term follow up studies are needed to test the hypothesis that these programmes affect adult physical and mental health, but the epidemiological evidence suggesting that they could is strong.

Successful implementation of the agenda defined in ‘*Our Healthier Nation’* will depend on research and development of such programmes. For this to happen doctors, and others who determine the allocation of NHS funds, will need to believe that emotional and social wellbeing are at least as important for health as physical wellbeing and invest both development and research funds accordingly.

[Germany uses a clear distinctive and effective health model. The German Health Model (Triple Aim) [Care, Health, and Cost] uses ‘Die Kur’ / ‘The Kinzigtal Way’. GP’s/Clinicians prescribe a preventative cure or a rest and rehabilitation week, which addresses ‘Whole Wellness’ from an emotional and mental outlook. This model is successful as it reduces stressors and improves mental health.

[Finland’s Health and Education System, places autonomy on schools which in turn allows alternative pedagogic approaches – by trusting parents, professionals and community, this in turn has led to an overall better placed education system, and an overall better environment where happier and healthier students flourish.]

REVIEW ESSAY: INCLUSIVE EDUCATION, EXCLUSION AND DIFFICULT DIFFERENCE: A CALL FOR HUMANITY?

Rogers

2012

It is clear that there are national and international government directives as well as legal obligations to educate and care for all children and young people.
For example, in the UK ‘Every Child Matters’ promotes a meaningful sense of well-being for all children, ‘Education for All’ is positioned as a global inclusive education strategy and the Individuals with Disabilities Education Act in the USA has influenced the levels of opportunities for disabled students. These are just a few of the policy contexts that address education as a means to promote inclusion and meaningful learning. But do they – really? A vast number of pupils are not included, have poor educational experiences and are either marginalised or demonised.

Slee (The Irregular School), Rose (Confronting Obstacles to Inclusion) and Smyth, Down, and McInerney (‘Hanging in with the Kids’ in Tough Times) all add different ways of thinking about disadvantage and inclusive education to the mix and yet seem to be underpinned by a similar critical discourse. That is, education is failing children and young people and therefore needs to be radically reconsidered, and it is everybody’s business.

Book One

The Irregular School: exclusion, schooling and inclusive education – Roger Slee - 2011

To contextualise, looking at exclusion, over a decade ago Young (1999, 59; original emphasis) suggested that ‘late modern societies consume diversity; they do not recoil at difference, they recast it as a commodity […].

What they are less willing to endure is ‘difficulty’. Slee, goes on to say that the late modern world ‘celebrates diversity and difference, which it readily absorbs and sanitizes; but what it cannot abide is difficult people and dangerous classes, which it seeks to build the most elaborate defences against …’ (1999, 59; ‘original emphasis’).

This is critical when thinking about inclusion and education, because although Young was talking about deviancy and criminality, here we see exclusion as an answer to dealing with difficult differences, whether they are disabled others who are difficult to teach, difficult others who are difficult to control or culturally diverse others who are difficult to understand (within a particular set of cultural norms).

Interestingly all three books reviewed here implicitly or explicitly address humanity, human differences or being human in one way or another. This may be why two of the three books highlight Martha Nussbaum's works, and suggests a level of understanding and enquiry that goes beyond the school and to thinking about inclusion as a broader political and ethical project (Allan 2005, Arnot et al. 2010).

What is also apparent in all three books is an engagement with community, rationality, care and ethics. This it could be argued, is the basis for an inclusive education – that starts with enabling human flourishing and care because 'being deprived of the capacity to develop supportive affective relations of love, care and solidarity [empathy/awareness] is therefore a serious human deprivation for most people: it is a core dimension of affective inequality' (Lynch, Baker, and Lyons 2009).

The main themes that seem to drive the narrative in '*The Irregular School'* are that of humanity, civility, waste, governance, justice and inclusion and exclusion. In many ways what Slee is doing in the first instance is setting the scene where there are many hidden (and not so hidden) exclusionary tactics going on in education globally; for example, **the current political state of inclusion is in contradiction with the testing and examination culture**.

'The rhetoric is of educational excellence'. This concept of 'failure' is talked about metaphorically using the medical term 'triage' suggesting, that those 'likely to pull through' (*The Irregular School*) will get more attention, than those likely to 'die' (or in the case of education, fail their examinations).

Competition and individualism compound a lack in human connection and hence lead to an uncivil society and exclusion. Who is to be included then? And as Slee asks: 'who will be left as the "normal child" once the cartographers of human disorders hang up their tools, dust off their workbench and fold their aprons?' (In this instance and for this report, [BWillicott v UK] highlights that the Primary Care Giver is the Mother (single), Parent, Carer as Educator and Researcher.)

Thinking about this in terms of human calculus, Young (1999) also talks of human worth by discussing credit ratings. As he maps a move from inclusion to exclusion he suggests the mode of exclusion is one that shifts and is also dependent on one's 'credit rating' from the wealthy, to the 'dangerousness of the incarcerated'. (Rogers 2007) suggests that there too is a 'credit rating' for people who are intellectually disabled, only their 'credit' is calculated within a mental ability, aesthetic beauty and 'appropriate' social interaction frame. It is this continuum of 'normality' that renders the child excluded and difficult with a very low 'credit rating' in terms of 'worth'.

Slee's position is that inclusive education is not simply about the education of disabled children and adults; it is everyone's business. How ethical is it to look away, to lack care? We know through research that, for example, young people who are excluded from school often end up in the criminal justice system (see also Confronting Obstacles to Inclusion).

Slee finishes the book (Irregular Schools) with propositions and tasks that, re-frame, re-right, re-search and re-visit all aspects of inclusive education he suggests it as a political project whereby schooling ought to provide ‘an education in democracy’, disband Ofsted and reconsider league tables. He questions whether we are actually capable of dismantling exclusion and any practices that feed it. ‘Are we capable? Not alone, we’re not’.

Book Two

Confronting Obstacles to inclusion: International responses to developing inclusive education edit. Richard Rose - 2010

‘Confronting Obstacles to Inclusion’ is an edited collection very different to the previous *Book One.* The sections take the reader through causes of exclusion, obstacles to inclusion, families, pupils as partners, professional development, teaching and learning, and support in the classroom. The chapters are written by education professionals, academics, mothers and researchers and use a range of methods to ‘speak to’ these issues, from, professional practice, empirical and policy research to personal experience.

Like Slee, Rose, turns to Nussbaum (amongst others) to highlight the fact that human society is struggling in general with differences that require a great deal of effort. Rose is suggesting a holistic and coordinated approach that addresses the cultural, political and socio-economic barriers that maintain many of the world’s population living in poverty and experiencing marginalisation while the gap widens between those with and those without.

Even though there has been a move towards and beyond the social model of disability which has had a huge impact upon disabled people’s lives, it seems globally the medical model is often sanctioned as a popular way of thinking about disability), and with regards to education this is certainly a barrier to inclusion as it fails to see education (policy and practice) as in need of reform, therefore leaving the child as problematic and often excluded.

This continued focus on the child (with apparent deficit) feeds a culture of blame, even though supporting families, suggest that families have additional and important knowledge about their child that can be tapped if a more community-based (and communication-based) approach was sought.

Currently policy discourse implies explicitly that parents are partners in the education process and yet is not experienced as such (see also Rogers 2011).

Importantly, in Section Three of the book, pupils' 'voices' are included. For example, Shelvin explains critically that pupils wanted to talk about access, ambition and achievement and then to voice their concerns.

Children wanted to be included when adults were making decisions about their lives and their futures. Moreover, they wanted to be prepared for adult life and currently did not feel that was the case. They saw education as a crucial place to learn not only about the formal curriculum, but about social, cultural and personal issues too. This aspect of 'hearing' about children and young peoples' experiences is critical in understanding their position and how they want to be educated, develop and indeed learn about 'life'. From the pupil to the professional, (Confronting Obstacles to Inclusion, 240): 'All the evidence suggests what is good for pupils with SENd, is good for all pupils in inclusive settings.

The most important thing in *Book Two* is that the authors suggest that learning takes place within and through relationships and these relationships are critical in developing a healthy sense of self. They argue that 'the poor' are not the problem – dismissing the view that poor families need to necessarily change and that teachers need to 'save' the disadvantaged students, and suggest the neo-liberal lens where 'we can all succeed in life if we apply ourselves' is far too simplistic and 'downright false' ('Hanging in with the Kids').

Thus it seems to be about relationships, power and pedagogy and it is suggested that if young people are not able to form relationships they then disconnect, disengage and subsequently 'drop out', and we all suffer as a consequence. The suggestion is that care, trust and respect are tantamount in developing a healthy learning environment. The authors claim that schools need risk-taking, innovation and experimentation – without which creativity is unable to flourish – and yet we exist within a risk society where no or low risk is positioned as the only way.

The position from the research above is that if you trust and respect the young learner to make decisions, then they will generally respond positively. They do however suggest that 'the broad intent was to create a better learning environment and strengthen relationships by having small groups of students with a team of teachers, some of whom are subject specialists' ('Hanging in with the Kids', 83).

Potentially problematic if we were to go down this road in thinking about learning communities, as we could see the 'special school' as one of the 'sub schools'. However, as an overarching theme it seems that they are proposing education within and for community and therefore adhere and propose inclusivity within a community-based curriculum. Smyth, Down, and McInerney suggest is that neo-liberal and neo-conservative discourses have worn away youth experiences by neglecting the meaning-making of the self and identity, and via the exclusion of student's real lives in education. **The restricted curriculum, tests scores and accountability of teachers restricts this link with their actual lived realities**.

Therefore, they suggest that there is a process of re-writing and re-righting identity into education via a humanising pedagogy.

Education, however, cannot survive on simply ‘heroic teachers’, but needs radical reform for both the schools and the communities (including LA’s). Ultimately what Smyth, Down, and McInerney suggest is that **policy is needed that develops good relationships with the community in partnership with parents** (see also Rogers 2011). Finally, we get to understand that many students have rejected school and those who do not ‘fit’ within the current system are seen as ‘toxic’ or ‘in deficit’.

There is however a choice of Home Educating, either electively or by forced ‘no alternative’ choice. (Government provides no assistance or funding, when home educating) It is the researchers own stance, that although Home Education is and does show positive and significant progress in a child’s learning; it takes away the accountability from the Government, who are wholly responsibly and accountably for its citizens by providing suitable, inclusive, specific needs based education for all.

*The article on ‘Home Education and Autism – Why do parents of Children with Autism Choose to Educate them at Home?’ describes the choices as a measure for substantial reasoning’s.

Book Three

‘Hanging in with the kids’ in tough times: Engagement in context of educational disadvantage in the relational school – Smyth et al. 2010

‘A possibility for tomorrow’ – suggests that we ‘dare to dream’ (‘Hanging in with the Kids’, 197) (not dissimilar to Slee’s ‘reasons to be cheerful’). They set up utopia in promoting a just democracy as a process of becoming.

The prescriptive curriculum and policies that we have now are like ‘wastelands’ full of language without grace or beauty, for example; we hear the likes of **best practice**, **clear goals**, **evaluation and results**, and they ask exactly what does this mean? The authors have said the participants (children) in this research want fun, respect and relationships.

The policy documents and directives are about and for children and young people in their learning and yet they omit fun, curiosity, kindness and compassion. If there is one message that screams, it is that education is more than training, which one could argue goes beyond the school and into further and higher education also.

Ultimately the ‘relational school’ is where students believe that their ideas and work really make a difference. The three crucial aspects of this relational school are ***‘relational trust’***, ***‘connectionist pedagogies’***, and an ***‘inclusive curriculum’*** (‘Hanging in with the Kids’) where there is a culture that supports all students to be successful in their own right.

This is sometimes risky, but innovation is risky. Taking the line that there is hope within the promotion of socially just learning is important. (Walking across the road is a risk; humans live in a risk-based world). Being critical of the status quo in the current climate is difficult, but they suggest being committed to change with an emphasis on relationships, pedagogy, school organisation and school–community engagement is crucial if we are to hope for utopia and social transformation and eradicate exclusion.

It is clear that Smyth, Down and McInerney’s critical policy ethnography is a great piece of research that is both empirically strong but also theoretically provocative and potentially reformative with regards to inclusion.

It seems that all three books are calling for a more creative and encouraging space for children and young people to learn in. In addition, education of all children and young people needs reform globally. ***All three books demand care and trust where educational leadership is inspirational and student voice is heard. What are they all calling for?***

Is it this?

> *‘a society that acknowledges its own humanity, and neither hides us from it nor it from us; a society of citizens who admit that they are needy and vulnerable, and who discard the grandiose demands for omnipotence and completeness that have been at the heart of so much misery and human misery, both public and private. (Nussbaum 2004,)’*

Home Education and Autism

WHY DO PARENTS OF CHILDREN WITH AUTISM CHOOSE TO EDUCATE THEM AT HOME?

McKerrow Dean

2012

> ‘The SENDist tribunal ruled (2014 & 2016) that Bastian’s chosen school would adversely affect the ‘tax payer’s purse’ / was not ‘best use of public resource’, even though the placement was cost neutral. (Schools are both state maintained.) However as Bastian’s mother faced an uncertain outcome and or having to place Bastian into a oppugning schooling placement, which would ultimately affect his disposition, positivity, self-esteem and self-awareness; the only other relative option was for Bastian to home educated so as keep ahead of the positive psychological continuum, whilst she undertook lengthy legal processes seeking resolve.
>
> Sadly, the Local Authority, ***illegally and unlawfully*** pursued Bastian’s mother via criminal courts for over two years, by claiming that she had failed to take Bastian to their chosen school and or that she was not ‘adequately’ providing provision based on his needs. The Local Authority finally withdrew and conceded on both of its summons’s and school orders [State Committed Crime], offered no apology and the family unit was left completely psychologically, mentally, financially and emotionally distraught.

So why did Bastian’s mother choose to home educate?

For this report we focus on the Term ***Home Educating*** rather than on Autism and McKerrow Dean’s account of schooling and environment.

McKerrow Dean states the following:

With apparent increases in the number of home educated children (Meighan, 1997) with special educational needs (Arora, 2006) including autism (Autism Education Trust, 2012) coinciding with increased dissatisfaction in the educational provision for children with autism in the UK (Batten et al, 2006 p11) and questions arising regarding reasons for home education including safeguarding issues (Badman), this extended qualitative research project aims to explored the reasons why parents of children with autism (Learning Disabilities) choose to educate their children at home.

‘Education Otherwise’ Annette Taberner, raised the following important point:

> *“Home education is a safeguarding measure where children are withdrawn from abusive situations **in schools** to be home educated”.*

However, without a strong leadership dedicated to genuine inclusion and professional development through rigorous training, then there remains no obligation or mandate to comply with the duties imposed on the Local Authority.

As Humphrey (2008) said, none of the strategies outlined in the above research question or elsewhere are likely to be successful unless they are underpinned by core values and attitudes that include respect for (and celebration of) diversity, a commitment to reaching out to all learners, a philosophy of excellence for all, and the notion that ‘inclusion’ is a process rather than a state.

Bullying and Emotional Barriers: Humphrey and Lewis (2008) make the point that increasing numbers of children with autism (both ASD and AS) who are educated in mainstream school face significant barriers which prevent them from making the most of their schooling experience. These factors may include stress and anxiety, bullying, social isolation, loneliness and inadequate support and training all leading to disaffection and a higher than average probability of exclusion.

Gunilla Gerland (1997) in describing her schooling experience wrote of her loneliness and solitude and that “*emptiness was my eternal companion*”. In their paper ‘B is for Bullied’, Reid and Batten (2006) reported the devastating impact bullying can have upon the child with autism (to the point of suicide) and reported that 44% of parents felt the schools did not act regarding bullying and in some cases the teachers themselves were responsible.

In his home-based education paper - “Not why does it work, but why does it work so well?” Meighan (1996) found that, wounds can heal, and children can recover from bad learning experiences, especially in the **supportive environment of a concerned family**. I have witnessed this too many times to think it is an unusual event.

Learning Needs and Consequences: Dawson and Osterling (1997) suggest that a supportive educational environment for those with autism should focus on the ability to comprehend and use language, an ability to play appropriately with toys (Howlin, 1997), **an ability to be able to interact socially with others, an ability to attend to their environment and an ability to imitate others**.

Interestingly, in their findings Barnard, Prior and Potter (2000) stated that where no autism specific provision was made in a special school, the parents were no happier than mainstream and that it was **inappropriate to place children with autism alongside children with other disabilities as there should be no assumption that their difficulties may be similar** (Warnock, 2006), the former frequently having learning profiles which may appear to be disordered, requiring very different support, (this is compatible with the views and experience of several of the parent interviewees).

[Education Act 1996 – as amended, SEND+D Act (SENDA) 2001 - Reinforcement of Inclusion in mainstream and or in special school. Revised COP – (2002) - Inclusion became a legal requirement.]

Their statistical findings demonstrated that more than a quarter of the parents who had children with autism in both mainstream and special school settings were dissatisfied with their provision.

Kammer (2009) wrote that many parents felt forced to remove their child from school and either home educate or find an alternative placement.

Findings, Analysis and Recommendations

Emerging Themes and Outcomes

Following examination of the reasons for educational difficulties within schools posited both by researchers in the field and reasons for home educating put forward by the parents, consistent themes emerged. McKerrow Dean defines:

‘A failure to address the criteria currently used for diagnostic purposes (that is social development, communication and rigidity in thinking and behaviour) or ‘*cluster of purposeful compensatory reactions’* as Bogdashina (2003) refers to them, became very clear. For the purpose of identifying a tetrad of debatably so-called impairments’, this section includes references to sensory perceptual experiences. All the parents made clear reference to the failure to recognise and meet those needs as being catalystic in their decision to educate their children at home: -

> *Parent (**M**) said:*
>
> The school said she was making progress, she could write the letter of her first name and hang up her coat, okay but she used to go berserk as soon as I got her out of the school. She was in reception class but kicked our windscreen so hard she broke it. Every day for two hours rampaging, meltdown, angry, screaming, throwing, school never saw this. She was using all her energy to cope at school, she had nothing left. We were looking for progress in communication and social skills because that was our main reason for her being there; school were not going to concentrate on these areas. Reading and writing didn’t interest her.

Further Emerging Themes

The next clearly emerging theme for deciding to home educate their children was very evidently that of bullying, emotional and mental health or safe-guarding issues.

> Whilst at school, she suffered severe depression, on many occasions wishing that she was dead. She was continually on edge, looking over her shoulder. Teachers said they were 'powerless' to do anything to help. It was unbearable, she was so badly withdrawn, went everywhere with her head down and her hand over her mouth when she spoke. She was a shadow of herself, was I to supposed to have keep sending her there? She would freak when at 2.30pm we couldn't be out anywhere in case any children from any schools might be coming out, it took us 18 months to be able to get to where we are now.
>
> ["An ounce of prevention is worth a pound of cure. It's more prudent to head off a disaster beforehand than to deal with it after it occurs."
> ~ 'De Legibus' (c. 1240)
>
> "Meet the malady on its way." ~ Persius (A.D.c 58)]

Outcomes Continued

The third outcome which was evident from the analysis as forming an agent for home education was that of personalised or individualised learning taking into account the unique learning needs of the children with autism including flexibility and curriculum: -

> *Parent (**M2**) said:*
>
> Our provision needs to acknowledge that there is no flexibility in staff, curriculum or environment. Schools need to work harder to meet individual needs, policy directives state it should all be personalised and individual learning and that's just SO missing. We need to be far more child centred with a personalised curriculum not based on the National Curriculum.

The question of Choice – Home Education

McKerrow Dean, stated that whilst undertaking her research she did not want to pigeonhole parents, and agrees with Fortune-Wood (2005, p3) that it was notoriously difficult to categorise individuals and whilst during her research interviewing process, one prevailing theme struck a chord; was that ***parents had a primal need to safeguard their children.***

> [Just as in the case of Bastian’s mother, she had lost the ability to work, in particular further her career, losing the family home, leaving her to be re-housed by the very same Local Authority who refused Bastian his schooling provision in the first place, in addition she has suffered financial, physical and mental health ruin, only surviving on state benefit’s, which works out cost negative and more than the cost neutral schooling placement.
>
> If the Local Authority / UK Government added the legal litigation and court costs for all 3 illegal and unlawful prosecution cases together with the first and second educational tribunal appeals, ECHR submission and a further combined discrimination and damages case still pending, together with the cost of rehousing and state benefits, they (LA/UK Government) would have saved a total of £600 000.00; as opposed to the refusing the cost neutral schooling placement, costing the state a standard £30 000.00 per pupil per academic year over the 5 years, equating to £150 000.00. Therefore, a total sum of £450 000.00 has been frivolously washed down the metaphorical barristers toilet.

Conclusion

A need to focus on social interaction, communication, language and imagination (play) skills including a genuine regard for the sensory perceptual differences their children experience. Safeguarding measures - Prevention of further damage to mental and emotional health caused by bullying and isolation including physical harm caused by self-harming remaining paramount. Creating a personalised programme of learning provided in an autism supportive environment taking account of **individual need**. Providing a flexible package of education often based on interests around a meaningful curriculum, based on strengths not weaknesses.

EDUCATION AND TREATMENT OF CHILDREN
Making Inclusion Work in General Education Classrooms
Obiakor et al

2012

The goal of any educational program is to help students maximize their performance.

For many students with disabilities, **the environment** in which to achieve this outcome is under continuing debate and sometimes diminishes the likelihood of achievement. As a result of a long and sometimes difficult history of treatment, individuals with disabilities experience educational professionals and service providers who not only downplay their capabilities and willingness to live a “normal” life, but who also argue that excluding them in educational processes is justified, proper, and right. We believe to increase normalcy in their lives, all individuals with disabilities should be educated with their peers without **disabilities in environments that are inclusive**.

The inclusion of students with disabilities in general education classrooms has stimulated great debate in education (Algozzine & Ysseldyke, 2006; Artiles, Harris-Murri, & Rostenberg, 2006; Kauffman, 2002; Kauffman & Hallahan, 1995; King, 2003). For example, King (2003) explained that “inclusive education means that all students within a school regardless of their strengths or weaknesses, or disabilities in any area become part of the school community.”

[**Whilst the researcher agrees with the principle of inclusion, she argues that inclusion per se, does not always provide the safest learning environment. What happens when the (LD) child fits neither a mainstream or special school placement?]**

Despite continuing debates about the applicability and practicality of full inclusion (see Kauffman, 2002), inclusion seems to have many positive derivatives. For instance, social justice is a grounding principle of inclusion since it supports respect, care, recognition, and empathy and challenges beliefs as well as practices that directly or indirectly encourage the continuation of marginalization and exclusion (Theoharris, 2007) Earlier, Fullan (2003) discussed these same proponents as essential characteristics in building an ethical school.

Within ethical schools, social justice is a major component of the belief systems of educators. Activities support achieving and maintaining environments where students are provided with equal opportunity to achieve an education.
In 1994, the world conference on special needs education, concluded that “regular schools with [an] inclusive orientation are the most effective means of combating

discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all" (Foreman & Arthur-Kelly, 2008).

Within inclusive classrooms, students with disabilities have access to meaningful, rigorous general education curricula; and special education is specifically designed instruction to assist them in maximizing their highest potential.(Algozzine & Ysseldyke, 2006; Causton-Theoharis & Theoharis, 2008; Ford, Davern, & Schnorr, 2001; Hockenbury, 1999)

Exclusionary practices, such as educating students with disabilities within separate facilities and outside of the general education are contradictory to the goals of inclusion and special education. Of course, the critical feature of successful inclusion is what happens (i.e., **services and evidence-based practices provided**) more than where it occurs (i.e., **placement or setting in which instruction is provided**).

In this regard, preferred, appropriate, and effective inclusive practices are guided by state and federal legislation, directed by codes of ethical and professional conduct, and defined by principles of effective instruction that are not bound by the setting in which children are taught.

Teacher educators, educational researchers, and policy makers are familiar with the foundations of inclusive practices. The purpose of this article is to discuss how general and special educators can make inclusion work in general education classrooms despite continuing concerns about its practicality. **Embedded in our discussion is the belief that inclusion works well when all stakeholders collaborate and consult with each other**.

Placement Fails to Define Least Restrictive Environment, Inclusion or Effectiveness

The process of providing special education services often begins by considering **appropriate and alternate educational placements** (Rizza & Morrison, 2003). It is important that all educators know how such decisions impact the daily lives of students, including access to the curriculum used to teach them and their **academic and social interactions with peers**. The least restrictive environment (LRE) mandate of the Education of All Handicapped Children's Act of 1975, the Individuals with Disabilities Education Act (IDEA) of 1990, and subsequent reauthorizations in 1997 and 2004 focused on inclusive practices.

According to Turnbull (2003), special education laws directed that students receiving special education must be educated with their peers without disabilities to the maximum extent possible and appropriate. Sailor and Roger (2005) argued that fully-integrated application of these principles has increased high-stakes assessment and sanctioned accountability outcomes for all students (see the No Child Left behind Act of 2001).

In many schools, there are different and thought to be **increasingly restrictive placement options for students with disabilities including *inclusion*,** where students participate fully in the general education curriculum and receive special education services as needed with their peers without disabilities; *resource* where students are pulled out and provided service outside of the general education environment, usually in the special education classroom; *self-contained* where students remain in and receive services in a special education classroom for the majority of their school day; and, *alternative* where students receive services outside of the general public school.

While placement does not define practice, placement decisions sometimes create "unrealistic expectations, prejudicial generalisations, illusory conclusions, and deceptive self-aggrandizement" (Obiakor, 2001); and continuing conversations are essential in efforts to make least restrictive environments and inclusion effective in providing services to individuals with disabilities. Students both with and without disabilities want to be educated within the same environment.

Klinger and Vaughn (1999) synthesised 20 studies that investigated the perceptions of learning of over 4659 students in kindergarten through twelfth grade. Of course, there are occasions where placement in general or special education does not result in improved academic or social outcomes for students with or without disabilities.

This is particularly true when few or no adjustments are made to meet individual needs (Obiakor, 2008; Williams & Obiakor, 2009). Conversely, there are occasions when students with disabilities make greater progress in general education than in special education. To a large measure, placement does not define practice and it is important to consider the following suggestions when making decisions about where to educate students with disabilities and their peers (Obiakor, 2001, 2007)

Race and culture can matter in the education of any student, but placements must be based on needs, not on students' racial or cultural identities.

- Language differences should never be misconstrued as a lack of intelligence
- Empathy is an important ingredient of a good educational menu
- Education in least restrictive environments is preferred, but ***practices*** are more important than placements
- Individual differences are not deficits and they must be valued in efforts to improve problems all students bring to the classroom
- All students are best served when their due process rights are respected
- Appropriate inclusion reduces biased exclusion of students in classroom activities
- ***Prejudicial placements have devastating effects on all students***

Guiding Principles of Successful Inclusion in a Reform-minded Age

General education accepts responsibility for and directs all students' learning and parents are encouraged to participate in supporting the model.

Conclusion

We understand that the practicality of full inclusion is debatable; however, we also understand that inclusion buttresses social justice, human valuing, and team-work. In this article, the premise is that educating students with disabilities within the general education classroom signifies that these students are not only members within the classroom and school community, but also are valued members within that community.

[For the purposes of this overview, the researcher acknowledges that a mainstream schooling placement or provision is not suitable, simply because of Bastian's spiky cognitive complexities, however neither is a specialist provision suitable for the same reason.

RESEARCH METHODOLOGIES AND METHODS CANNOT BE VALUE FREE

John G.M.

2015

“Values are our inheritance, what makes us what we are as a people.” (Barack Obama, 2006)

[‘It was always going to prove herculean and arduous when gathering the cross-sectional disciplines associated to Bastian and or others like him, as the complexity and plethora of publications intersect such a diverse range of theory and imperial data in all of the above areas.

The researcher however, rather than using a direct theoretical argument, focused on an overview of the pertinent theories, evidences and data, so as to correlate, support and arguing the case for [BWilicott v UK] which highlights the adverse effects were a child of SEND to be placed in an oppugning school environment’ – (Willicott. 2016)]

John, states: “The debate whether or not research methodologies and methods can ever be value free is of great interest to researchers and policy makers worldwide. Therefore, the assertion that ‘research methodologies and methods cannot be value free’ needs to be critically questioned, discussed and considered by anyone who is involved with research.

Research methodologies are the different systematic processes involved in unravelling an underlying theory or line of research.

However, the researcher’s chosen methodologies and methods will usually correspond directly to the suitability and relevance of their own underlying theories relating to their own field of research. Clarke (2005) suggests some of the research methodologies might include historical, comparative, descriptive, correlation, experimental, evaluation, and action, ethno-genic, feminist and cultural systematic processes.

Furthermore, any type of research which involves people will inevitably take place within a social setting. Therefore, social research can never be without its challenges and limitations, as rarely will there ever be one viewpoint about anything in any one social setting. This is because all individuals carry with them their own personal viewpoints, background, interest and values which unavoidably will influence their choices.

As David Blunkett (2000) states, “Very little research in the social and educational field is or can be entirely value free ... [and if] we are to reach a better level of communication between researchers and policy makers it is right to expect both researchers and the users of research to be more explicit and self-critical about their underlying assumptions and values. (Carr, 2000, p.437)

Whilst the researcher has spent 24 months gathering the various published evidences, data and or supporting neurological materials in support of [B Willicott v UK] the overriding factor has always been to establish a truthful and transparent research process, so as to highlight complex cases, or those who do not fit into any ‘box’.

John, (2015) highlights, “As Greenbank (2002) emphasises, the researcher should always attempt to assume a ‘reflexive’ style by endeavouring to be as truthful, transparent and open about his/her own values and show how these have affected them throughout the research process.

Ontology & Epistemology

Sikes (2004) states that “Usually, the most significant factor that influences choice and use of methodology and procedures is 'where the researcher is coming from' in terms of their philosophical position and their fundamental assumptions concerning:

- *Social reality - their ontological assumptions;*
- *The nature of knowledge - their epistemological assumptions;*
- *Human nature and agency - specifically their assumptions about the way in which human beings relate to and interact with their environment“ (Sikes, 2004)*

Ontological and Epistemological Positioning

John, in her personal positioning states:

“There are some very significant factors that have influenced my values and have allowed me to bring a very personal dimension to the paper. During my BA(Ed) degree I discovered the powerful link between neuroscience and educational potential. At the time I was enjoying a magnificent social life and without putting much effort into my studies was consistently achieving B’s and C’s.

My father had successfully facilitated a change in my attitude, motivation and commitment towards my studies which consequently produced a significant shift in my performance data. Unwittingly I learned how qualitative methods could be used to positively affect quantitative scores. This experience has profoundly affected my own teaching methods, as I have always used meaningful reward to increase motivation and academic performance during my lessons.”

John further argues: “This in itself is actually a powerful link between neuroscience and education, as use of meaningful reward increases the dopamine levels which will cause people to want to repeat the experience. Interestingly, increasing dopamine levels has the same effect as the drug Ritalin, which is commonly used to treat ADHD."

Coppersmith's research (1967) still influences her practice today. The research found that the three most influential people who shape the child's own perception of themselves were **parents**, **peers** and **teachers**. He gave evidence to show that teachers and peers have two thirds influence in shaping either a positive or negative perception in a child. I have successfully used this to significantly increase pupil self-esteem, to influence the children to choose more acceptable behaviours towards each other and to change their own negative perception about themselves.

John says her research led her to examine reasons for low literacy attainment,

"I began researching the effects of low self-esteem, behavioural difficulties and dyslexia tendencies upon children's literacy performance. - As SENCO at my school - I wholeheartedly believed in the power of children's voices in research and believed to view learning experiences from their eyes, as well as the eye of academic literature and significant others.

Upon reflection of my values, I tend to take a social constructivist interpreventist stance and it is clear to see how my own values define who I am as a person, researcher and educator, having greatly influenced my own choice of research interests, methodologies and methods."

John (2015) Research Analysis of the Paper:

'RARE CHROMOSONAL DELETIONS & DUPLICATIONS IN ADHD: A GENOME WIDE ANALYSIS '–*MRC Centre in Neuropsychiatric Genetics & Department of Psychological Medicine & Neurology Cardiff. The Lancet 2010 volume 376 (9750) pp1401-1408*

Upon closer examination of the paper, negative words like 'deficit', 'disorder' and 'disability' are used about the children. Casey Edmonds (2012) believes that negative terminology is not helpful, suggesting the more positive word 'diff-ability' instead of 'disability'. The medical model takes the stance that those with a 'disability' are not 'normal' but are 'broken' in some way.

Medical methods to manage medical problems are usually dealt with through medical treatment, such as drugs. However, the negative affect of promoting ADHD as a genetic cause encourages people to rely on drugs as the only biological answer. Shockingly, Schlander (2007) estimated the annual cost of prescribed drugs for children with ADHD in England would exceed £78 million in 2012.

[For the purposes of this report, the researcher looked at John and how she used *Dopamine* in her research methodologies, as dopamine is regulated by experiences through environment, directly relating to Bastian and his complex case.]

The social model of ‘diff-ability’ believes that all barriers to potential should be removed and environments adapted to eliminate social injustice caused through discrimination. As educationalists we have a legal obligation to do our utmost to enable all children under our care to reach their full academic potential regardless of their learning style, label, personality type, ‘disability’ or ‘diagnosis’.

As educationalists we have a responsibility to ensure social justice for all our children, by actively promoting equality and effective inclusion within our learning environments regardless of whether or not they fit into the neat ‘normal’ box. In fact, our ultimate aim is to realise and unlock the unique potential of every child. Therefore, we should be striving to stimulate originality, individuality, creativity and innovation within our learning environments.

The social model seeks to celebrate unique human differences and the richness of neuro-diversity by recognising that all human beings are different and ‘one size does not fit all’. The main goals of neuro-diversity include acknowledging that neuro-diverse people do not need a cure, changing the negative language from the current “condition, disease, disorder, or illness”, broadening the understanding of healthy and giving neuro-diverse individuals more control over their treatment, including the type, timing, and whether there should be treatment at all. (Fenton et al, 2009)

Department of Education, (DfE) state: “Parents and teachers may not be accurate observers and reporters of the child’s behaviour and mental state. These non-expert observers may be not only inaccurate but systematically so, either because they have only a partial picture of the child’s behaviour or because they are subject to bias in some way.” (DfE, 2012)

Cohen, Manion & Morrison (2007) point out, “It is very easy to slip into invalidity; it is both insidious and pernicious as it can enter at every stage of a piece of research.” (Cohen, 2007)

Another way to avoid further invalidity would to have an unbiased research team, including both insider and outsider researchers. However, another issue of bias is found outside of the paper, since their sponsors have entrusted interests in finding a genetic or biological source and will inevitably be promoting their own particular agendas.

For this report context, the researcher uses John’s stand out paragraph:

‘The authors used ‘Child ADHD Teacher Telephone Interviews’ and acknowledged that ‘symptoms and impairment at school are a diagnostic requirement of the disorder’. However, this research method relies completely on the **subjective opinions of the teachers and is not like a fixed procedure where laboratory tests are used and measured**.’

[**Local Authorities instruct, biased Local Authority Staff (often ill trained and uninformed when it comes to rare diseases and or complex psychological and**

neurological interventions), to unlawfully 'assess' a child for no more 10-20 minutes; in the case of Bastian, a totally of 19 minutes was used to 'holistically assess' and assume via biased views, that they could provide suitable provision.]

With an interview method, a skilful interviewer can follow up ideas, probe responses and question different perceptions, as an interview is a conversation between interviewer and respondent. However, there is always a danger of bias in interviews, as an interviewer can ask leading questions and their tone can produce a desired answer. In fact, with an interview, it is difficult to see how bias can be avoided completely.

From an educationalist's point of view I would be very interested to know if the teacher was questioned about their own personal preferred teaching style, classroom management strategies or if they had set up an effective inclusive multi-sensory teaching environment to facilitate the different teaching styles of all the children within their class and if these had made any impact upon the children's behaviour. The Elton Report (1989) identified 80% of disruption in schools as being due to poor classroom organisation, planning and teaching. (DES, 1989)

This shows that teachers can significantly influence motivation levels and on task behaviour through providing highly effective teaching through preferred learning styles & effective support given in our class environments.

By strategically planning meaningful motivation reward into the classroom routine it will encourage on-task behaviour, as well as increasing dopamine levels. Research shows that increasing dopamine levels has the same effect as Ritalin drugs, without the side effects. As Volkow et al (1998) points out, ADHD has been linked to inhibition of the dopamine transporter; Ritalin consequently increases dopamine available for 'synaptic transmission'.

Surely if we can increase our children's dopamine levels naturally within our classes, we can use neuroscience to positively affect the educational and behaviour performance of our children in school without the horrible side effects of drugs. Surely linking neuroscience to education would be a significant area for future research!

> *Gibbons and Silva (2008) found that children's behaviour at school depended upon three factors; a) whether the child enjoys school, b) whether the child is bored at school and c) whether the child dislikes his teachers.*

The authors measured the ADHD children's IQ scores using the Wechsler Intelligence Scale for Children to inform their studies. Why didn't they measure the control group's IQ? GCA scores are subject to change depending upon how effective the strategies and interventions are to influence and increase quantitative scores. As previously mentioned my (John) own university averages shot up from a consistent 50% to consistently achieving straight A's. Did my IQ change? No, but my motivators did, which in turn significantly influenced my attitude and engagement of learning.

I have also observed a psychologist carrying out a cognitive assessment test and have witnessed elements of bias within tests which required multi-choice questions. One child's NFER score went up 10 points after he ticked all the (a) choices without reading any of the questions.

Conclusion

In conclusion, researchers who claim to be value free are deceiving themselves, since our values affect everything that we do.

Therefore, as John so accurately states:

"As the research paper demonstrates, all research is inevitably affected by both explicit and implicit values. We are all influenced by our experiences which affect in turn will affect ontological and epistemological positioning. Even 'objective' scientific research methods are full of bias and cannot be value free as their theoretical stance is reflected in their choice of methodologies and methods.

As the research paper demonstrates, values will determine a researcher's purpose, hypothesis and what they choose to put in or leave out of the entire research process. A person's values will inevitably influence their research choices, the methods that they choose and how they interpret and report their results. Therefore, we all should be careful how our own values might interfere with our interpretation of the work of other researchers, and before evaluating the effectiveness of any research we should evaluate our own positioning as well as the researcher's underlying values.

As Teddlock, B. (2005) states, "Researchers and participants are united by a set of ethical values in which personal autonomy and communal well-being is interlocked." (Teddlock, 2005, p.9)

Therefore, future research should no longer be genetics against environment, but should combine a range of research methods and methodology. For example, investigating about what are the most successful environmental interventions and strategies that can be implemented to bring about positive neurological changes and dopamine release through meaningful reward in the 'ADHD' brain.

Workplaces and schools need to be 'ADHD' friendly and inclusive, working with the pupils' strengths and talents not against them, as teachers can set up clever systems to focus these energies positively to raise the self-esteem and the academic levels within classes. **Additionally, the children's ideas and input should be at the heart of any research which involves them**.

Thus, there is the necessity for future exploration of effective interaction between the different disciplines, linking neuroscience and education in order to challenge institutional practices and to promote effective inclusion for all throughout a variety of settings. Often raised conflicts of ideas, principles and interests are an important requirement for the development of new research ideas leading to more effective practice.

Therefore, inter-disciplinary and trans-disciplinary research dialogues between the distinct 'truth' of the humanities and sciences are needed, as well as the requirement for a more user-led approach to research. Consequently, it is time for the different professions to interact with the academic truth of other disciplines, in order to broaden, strengthen and re-evaluate their research practices, since as this assignment shows research methodologies and methods cannot be value free.

As Kennick (1998) states, "Only a fool would deny the importance of evidence…Best perhaps to seek honesty not truth. Caution rules OK." (Kennick, 1998, p.1824)

[As this report has highlighted, – The Voice of the child is protected under the Child's Rights Charter – The Child therefore has a Voice; however his/their voices MATTER, so when removing their voice, it could be considered as the child being oppressed.

In this report, the researcher has remained neutrally grounded by using an overall holistic view point when covering all specialisms that pertain to this complex yet easily resolved case; thereby being respectfully open and reflective, coherent and thorough when overviewing the position of the child (Bastian).

Bastian was asked the following question:

"Bastian, how are you feeling, and how has this very difficult schooling situation, made worse by the Local Authority, made you really feel?

Bastian:

"I feel like I am no one, that no one listens to me, I feel I am invisible, I am not allowed to express myself, or inform others of I how I am, I not allowed to feel or state how I see myself"

Bastian's response indicates and highlights his oppression, which John descries above.]

A PSYCHOANALYTICAL ANALYSIS OF OPPRESSION
John G.M.

2014

The purpose of this paper is to conduct a psychoanalytical analysis of oppression.

Employing Watermeyer's argument, this paper explores oppression through the lens of psychoanalysis, exploring psychoanalysis as a vehicle to release emancipatory possibilities for effective change. Since oppression typically operates as a system that has multiple forces which take away someone's power, with all of these forces typically working together to marginalize, subordinate or devalue people, most dis/abled people will have experienced some form of oppression throughout their lives.

John states: This paper aims to embrace theories that expose some of the hidden processes of oppression that are produced by different relationships, institutions and systems.

Additionally, internalised oppression will be explored through the lens of dis/abled subjectivity, using reflections and accounts of discriminatory interpersonal and institutional processes that exist throughout society. Therefore, this paper creates an open space to explore oppression that is often hidden from view, reflecting upon the personal experiences of others, in order to reflect how effective tools can be developed to empower and equip 'the dis/abled other' with a voice to create and influence positive emancipatory change.

> *"Freedom is never voluntarily given by the oppressor; it must be demanded by the oppressed." Martin Luther King.*

Oppression is an unjust use of power, which enforces an unequal relationship and denies another's rights or values. Watermeyer (2013, p.38) defines oppression as "a unidirectional force exercised on faceless individuals who are altogether subjected to a crushing ideology – a system of villains, victims and malevolent hegemonies to be overthrown."

Oppression can be an act, an attitude or a system which causes suffering and harm to an individual or group. Oppression and the marginalisation of the 'other' are often provoked by a **perceived difference which can take on many different forms and can appear in many different disguises**.

Synonyms of oppression include exclusion, ill-treatment, harassment, discrimination, cruelty, pain, subjugation, injustice, exploitation, abuse, suffering, persecution, maltreatment, tyranny, despotism, repression, inequality, control, suppression, subjection, enslavement and exploitation. Antonyms of oppression include freedom, choice, equality and inclusion.

Johnson (2000) demonstrates, “For every social category that is privileged, one or more other categories are oppressed in relation to it. The concept of oppression points to social forces that tend to press upon people and hold them down, to hem them in and block their pursuits of a good life. Just as privilege tends to open doors of opportunity, oppression tends to slam them shut.”

Therefore, this paper seeks to conduct a critical psychoanalysis of oppression, in order to question and challenge the causes of inequality and discrimination towards ‘the disabled other’. Since oppression is often experienced in hidden and invisible ways, it can become deeply internalised through the oppressed group unconsciously adopting the negative attitudes and beliefs of others towards themselves.

This needs to be confronted and brought completely out into the open by reflecting upon the actual individual accounts of oppression from ‘the dis/abled other’s’ perspective. As Fanon (1952) states, “A story that takes place in darkness, an internal darkness” needs the light to “shine into the smallest crannies.”

In Pedagogy of the Oppressed, Freire (1970) points out people become ‘dehumanised’ through oppression from their oppressors, but that they can achieve ‘humanization’ again through recovering their freedom. As Zola (1994, p.85) points out, “**Oppression does not only involve the loss of voice but also the tools to find it.” However, dis/abled writer, French (1993) argues that the reality of an oppressive free society is a very dangerous and idealistic myth**.

Therefore, this study will employ what Watermeyer (2012) defines as a critical psychoanalytic perspective, which will look at oppression through the lens of dis/abled subjectivity, using accounts and reflections of discrimination from the perspective of the ‘dis/abled other’.

> ***As Watermeyer (2013) points out, “If oppression is to be overcome, all actors within a social system must look inward.”***

John discusses: “I have always been interested in developing inclusive education and practice, personally engaging with effective inclusive child led research, as well as using grounded theory with adult mental health service users. I have successfully experimented with combining social and medical models in different settings, observing positive behaviour changes and life-changing effects.

These results have significantly and profoundly challenged my own thinking and changed my own practice of relating, as well as confronting my own beliefs about traditional education models and mental health institutional practices. I have also noted, along with Thomas' (2007), that 'barriers to being' show that disability is strongly associated with low psycho-emotional well-being."

As Goodley & Lawthom (2011) show, "Psychoemotional disablism prompts us, as researchers of communities, to think critically about the relationships, reactions and responses of the community (the other) to disabled people (the self) in our own and other countries."

It is my opinion that there are **countless vulnerable people in our society who are being oppressed and are often trapped in systems without a voice**. I believe that there are numerous effective strategies that can be implemented to reduce oppression, to provide solutions and initiate change within our schools, mental health settings and throughout the whole of society.

It is my opinion that there needs to be more space for **grounded theory user led research**, and for researchers to use this information to powerfully affect change towards developing a more inclusive, less oppressive society, whereby all have equal access and opportunity regardless of differ-ability within education and society as a whole.

Reasons for a Critical Psychoanalysis of Oppression

"The most potent weapon in the hands of the oppressor is the mind of the oppressed. If one is free at heart, no man-made chains can bind one to servitude, but if one's mind is so manipulated and controlled by the oppressor as to make the oppressed believe that he is a liability…then there will be nothing the oppressed can do to scare his powerful masters." (Biko, 1978)

Psychoanalytically grounded studies of oppression have attracted increasing interest from theorists exploring issues surrounding oppression and disability studies (Watermeyer, 2008). It appears that psychoanalysis has emerged as a useful and important tool for uncovering the unconscious and often unspoken hidden feelings of the 'disabled other'. As Mason (1992) points out, "We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons, with which to re-injure ourselves, every day of our lives."

[Bastian has and still is participating in psychoanalytical therapy, and has been doing so for over 7 years, this therapy gives/allows Bastian the ability to understand his positionality and disposition so as to overcome and cope with his obstacles (disabilities) thus enabling him to have his own view point and independency; yet, this entire avoidable legal battle has been the opposite of what the government seek to achieve, simply by disallowing him his own voice, 'forced oppression' – which is a clear aversion of policy and legislation.]

Therefore, as Watermeyer (2012) explains, “Critical psychoanalysis is a theory that allows us to explore the ways in which we are taught to feel inferior.”

However, this theory should be examined against the background, history and other arguments presented about oppression of the ‘dis/abled other’. This approach was not challenged by the Government until 1970. In 1970 the Education (Handicapped Children’s Act) stated that all children, including those with dis/ability, were entitled to an education. This was a hundred years after the education system first began in 1870. Until 1970, the ‘dis/abled other’ were perceived as being uneducable, being the responsibility of the Medical Health Service rather than the Social Education Service.

However, it wasn’t only the educational provision that needed challenging, societies’ attitudes towards ‘the dis/abled other’ also needed to change. It was not until 1970, that the term ‘handicapped’ was used to describe SEN children, who were seen as being different from the other children who were able to successfully access schools.

People began to question the accepted practice at that time and it was deemed necessary to give different labels to define the ‘dis/abled other’. Definitions of dis/ability have changed frequently to suit the acceptable terms used in society. As Sinason (1992) points out, “No human group has been forced to change its name so frequently.”

Therefore, the social model of disability began to question acceptable rights and boundaries. As Watermeyer and Swartz (2008) states, “The social model is centrally concerned with the political aspects of disability – a crucial contribution of this model is the insistence on a socio-political rather than an individualistic level of analysis.”

Current developments of the Human Genome Project focus on ‘impairment’ in prenatal testing and raises concerns about the lack of value that societies attach to lives of the disabled. (Shakespeare, 1998) However, the social theory celebrates the richness of human diversity and the richness of neuro-diversity by recognising that ‘one size does not fit all’. The main goals of the social model is to acknowledge that people do not always require a cure, but instead widens the definition of healthy, giving all individuals more control over whether they want medical treatment or not (Fenton et al, 2009).

As Marks (1999) points out, “Many social model theorists have not…seen the analysis of ‘experience’ as being relevant to our understanding of disability.” However, as Watermeyer and Swartz (2008) highlight, “There may be a danger through ignoring the psychological approaches that the belief may be reinforced that a layer of disabled people’s lived experience is illegitimate and to be obscured – even rendered inadmissible – if there is to be hope of real movement towards an equitable society.”

Therefore, it is important to use an overlapping and interdisciplinary approach of medical, social and relational, as well as an understanding of psychoanalysing the unconscious thought. Carol Thomas (2007) strongly argues for a trans-disciplinary space, which breaks the boundaries between the traditional disciplines of ‘medicalized’ views of disability with social models of the dis/abled other. Marks (1999), agrees and adds that “Individual and social models of disability represents different sides of the same coin.

Both are necessary for the survival of the other.” However, Finkelstein (1996) argues that the social model in disability studies is being ’diluted’ by individual accounts which distract from collective barriers that disabled people face. He criticises evaluating attitudes and emotions that come from oppression and has argued against Morris (a dis/abled writer). Finkelstein (1996, p.11) believes that by listening to the subjective experience of the dis/abled other, this encourages a “shift away from thinking about changing the real world.”

Watermeyer (2012, p.163 & 164) also shows that, “The social model movement in disability studies has supported an unspoken assumption that disabled people, despite their experience of profound injustice, remain psychologically unaffected by this suffering.” However, as Marks (1999) argues, “Some experiences are so painful that they cannot be consciously experienced.”

Therefore, a critical psychoanalysis approach is necessary as it examines that which is deeply hidden behind conscious thoughts and actions, but at the same time incorporates and responds to lived experiences. (Martin-Baro, 1994; Watermeyer, 2013)

Therefore, it is my opinion that psychoanalysis should be used in combination with grounded theory, as accounts of oppressed groups are well established within the study of psychology (Martin-Baro, 1994) As Watermeyer (2012) suggests, “A combination of critical psychoanalytic insights and the participatory methods of liberatory and feminist psychology hold promise in driving disability transformation.”

Moreover, Morris (1992) demonstrates that ‘traditional’ psychologies pinpoint the ‘problem’ within individuals who are impaired by their difference. However, she argues that this psychology has missed the opportunity to explore subjectivity as tool for change and shows how ‘psychological inquiry can be shifted from a mode of oppression to a source of subversion’.

However, Watermeyer (2012) points out that, psychological studies about people with dis/abilities have deliberately avoided examining the psycho emotional experience, as it was thought that this would exaggerate existing ‘stereotypes about disabled people being helpless and damaged’.

However, where the medical and social models have failed to involve individual’s personal experience and insight, psychoanalysis can offer another approach to produce a better-rounded and balanced understanding of oppression from the point of view of the oppressed. As Morrison Van Voorhis (1998) writes, “Fully listening to people on the margins is a revolutionary act because their lives and experiences are typically ignored.” Surely, the voices of marginalised and ‘the voices of their children’ should be heard first. (Smith, 2011)

Therefore, psychoanalysis can provide a useful method and space for ‘the dis/abled other’ to speak and be listened to, as well as accurately ‘describing of the workings of oppressive social realities that the key to unlocking them resides.’ (Watermeyer, 2012)

“Ownership is the key to recovery. We must learn to own our experiences, whatever they are. Doctors cannot own our experiences, psychologists cannot own our experiences, nurses, social workers, support workers, occupational therapists, psychotherapists, carers and friends cannot own our experiences.” (Coleman, 2011)

Therefore, psychoanalysis is an approach which can be used to listen and involve the marginalised ‘other’, to express their thoughts, feelings and experiences. Psychoanalysis and a reflection of personal experience can give the oppressed a voice and a raised platform, to present well-constructed arguments to challenge oppressive systems and to empower people to wage war against oppressive practices.

As Watermeyer and Swartz (2008) states, “We need to reclaim our personhood, our choice – own our ambivalence and examine our self-identities – if we are to move and cohere and find personal power. The history of disabled people is a history of being coerced into allowing others to define one’s experience and, hence, oneself.

In denying our loss, where this obtains, we deny ourselves. Often, we do this by allowing ourselves to be dictated to by the need to disprove what is assumed about us. We lose our own reality, our own experience, our own self, and possibly in the process our healthy capacity to relate to and be seen by others, as we are impaired in our capacity to see ourselves.”

Due to their vulnerability, dis/abled people are very often forced into situations or have to surrender to being whatever they are told to be. As Watermeyer (2013) illustrates, very often disabled people who may find themselves on the negative side of a split often believe that they deserve to be abandoned, abused or punished by the ‘normals’. As Grant (2013) shows, “Other agents can render me unfree by inducing in me a false belief.”

As Watermeyer and Swartz (2008) point out, “This internal experience may be relegated to a shameful, unseen corner of the self, rejected and disowned not only publicly, but perhaps also in privately felt accounts of self-identity and history.”

As Watermeyer (2012) states, “If anyone is surprised that lives of relentless denigration, senseless exclusion, distorted socialisation and countless forms of discrimination shape and affect personalities, I am not.” Pellegrini (2010) also points out, “Emotionally charged and unboundaried educational settings where splitting and projecting flourish…can put at risk the functioning of individuals and organisations.”

Another service user revealed that during health care appointments with professionals, he is often ignored by doctors and psychiatrists who talk to staff about him, rather than directly communicating face-to-face with him. It has been his experience that during many appointments, professionals will often treat him as if he is not there. Instead he frequently has to listen to conversations, opinions and decisions being made about him without anyone considering his thoughts or feelings. As Zizek (2008) writes, “The other is just fine but only insofar as his presence is not intrusive, insofar as the Other is not really there.” (Zizek, 2008)

However, as Watermeyer and Swartz (2008) write, “All humans require validation and acknowledgement, particularly of our more painful and difficult experiences, in order to foster self-compassion and acceptance. What we describe in the lives of disabled people is a pervasive cultural patterning surrounding this issue, which works to starve disabled people of this experience of being truly ‘seen’ and accepted.” Additionally, Shakespeare (1998) believes that disabled people have the right to be ‘treated equally, should be included rather than excluded from society, and should have the right to be heard, regardless of physical or intellectual endowment.”

Therefore, in order to develop inclusion within society and challenge the stigma attached to disability, all layers of society need to transform their thinking to ‘promote forms of personhood and relationality that value disabled people as key contributors and participants.’ (Goodley and Lawthom, 2011)

[The researcher again highlights Bastian’s self-awareness and again submits his question: “Why am I not allowed to feel the way I feel?”]

Conclusion

” The oppressed not only stand to gain from social activism by being activists themselves and by benefiting from the resulting changes, but are also best situated to see, understand, and document the pressing need for bettering our society for the good of all.” (Ali and Lees, 2012)

In conclusion, an exploration of psychoanalysis of oppression through the lens of dis/abled subjectivity, using reflections and accounts of discriminatory interpersonal and institutional processes that exist throughout society, alongside a working knowledge of psychodynamic defence mechanisms can be useful in helping to further understand the processes behind oppressive practices.

POSITIONALITY (INCLUSION) – DOCTORAL SUBMISSION

‘Exploring exclusion and reasons for educational failure; Neuro-diverse youth-led narrative inquiry, interlinked with trans-disciplinary and inter-disciplinary dialogue to address educational and social inequality.’

John, G.M.

2016

[The researcher, by way of positionality, turned to John, G.M. (2016) as a reference point, when setting out a plan so to gather as much empirical and theoretical evidence as possible.

Here, John (2016) sets out her own positionality when researching the topic of inclusion and her driving passion in removing barriers to learning and ‘being’ which in turn has developed into a trans-disciplinary setting, including mental health, social services, policies, school systems, and the wider society for all, regardless of age, class, or person’s location on the neuro-diverse spectrum. She in turn used (Edmonds, 2012) as her reference point.]

Johns goes on to say: Since I believe that effective inclusion is a commitment to valuing others by promoting an acceptance of their differences by deliberately removing barriers and maximising learning opportunities for all, my primary research aim is to remove all barriers to individual potential and to see effective inclusion for the most vulnerable people in our society. I believe that understanding one’s positionality means knowing where you stand with respect to power and this is an essential skill for social change agents.

For it is only from an understanding of your own positionality, that a person will have a standpoint from which to challenge existing power systems and to bring effective meaningful change. Since social change always occurs within the context of existing power structures, researchers and activists must always confront existing power structures in order to bring effective change.

Moreover, sometimes a person has to come out of a system, in order to change it. However, as Beresford (2003) emphasises, “**The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.**” (Beresford, 2003)

Reflexive researchers comment upon, debate, modify, and represent principles and values through manipulating features in different ways. Reflexivity shows that people have both self-awareness and creativity in research, which leads to innovation. I am totally committed to innovation that affects change, challenges tradition and improves practice.

As Sharples et al (2012) states, “Seamless learning is when a person experiences a continuity of learning across a combination of locations, times, technologies or social settings…it may form part of a wider learning journey that spans a person’s life transitions.” (Sharples, M. et al, 2012)

[John, goes on to state that it wasn’t until her own BA (Ed) degree that she discovered the connection between neuroscience, motivation and educational potential.]

As William Temple states, “Are you going to treat a man as he is or as he might be? Morality requires that you should treat him as he might be, as he has it in him to become…Rising what he is to what he might be is the work of education.”

The academic literature showed that children’s behaviour in school is the product of a number of interrelating systems, including the family, the peer group, the playground, the classroom and the school, and the relative importance of each varied from one child to another. - As Moyles (1992) demonstrates, “Individualisation is often the key to success, for if the teacher knows each child and the child feels valued by the teacher, then even within group and class settings the teacher can acknowledge understanding of the child’s needs.” (Moyles, 1992)

John further discusses: Through conducting research and committing to my own continued professional development, this caused a significant shift in my positionality as a teacher and also as a researcher. The research highlighted many future recommendations; however it became my driving focus to make school a place whereby all children would be “treated by those in authority with the patience and respect that they so much need and deserve.” (John, 1998)

My positionality as a researcher and my experience told me that the only way to solve a massive problem like this was to strategically plan and research my way out of it, involving the children in every part of the process.

Therefore, I pulled upon all my skills as a researcher, since I had experienced previous rapid effective change and success using specific child led research methods. I immediately started to strategically plan using a triangular method of action research, self-evaluation and observation. As Mouly (1978) points out research through the planned and systematic collection, analysis and interpretation of data is, “A most important tool for advancing knowledge, for promoting progress and for enabling man to relate more effectively to his environment to accomplish his purposes and resolve his conflicts.” (Cohen and Manion, 1994)

John, (2016) goes on to open up about her findings when discovering how the residents (her ‘befriended youngsters in a ‘locked mental health ward’) were motivated by her very positive disposition and how a particular boy was motivated in her own teaching class.

“I found that by using meaningful reward in class it increases the dopamine levels which will cause people to want to repeat the experience and behaviour improves, demonstrating a powerful link between neuroscience and education. (McIlhaney and McKissic Bush, 2008) I was able to recognise that his strong motivator factors were digital learning activities and outside learning activities.”

DfES (2004) set out the Governments vision for SEN through ‘Strategy for SEN Removing Barriers to Achievement’. It highlighted early intervention, removing Barriers to learning, raising expectations and achievement, delivering improvements through partnership. (Hayward, 2006) By using child led action research and listening to their voice, I found that I was able to meet all of the four key Government SEN targets.

Such was the power of the children’s voice in research that I began to view learning experiences from their eyes and together we developed highly effective inclusive systems of learning based upon their favourite learning styles which were digital learning and outdoor learning. (Luskin, Bonwell and Elson)

John, (2016) continued observing her ‘befriended young people in a locked mental health ward’ and noticed the following: I noticed that some of these young adults began to change their behaviour. I was only using the same effective teaching strategies of raising expectation, removal of barriers, developing effective relationship, listening to them, valuing them, treating them with dignity and speaking hope of a better tomorrow.

One youngster was quite isolated and did not have many friends, so I bought him large boxes of crisps. Very soon, he was the most popular patient on that ward, as he became the unofficial ‘tuck-shop manager’. I also bought him a mobile phone so he could have contact with the outside world. He verbalised that regular texts were a ‘life-line’. One by one, we saw all of our ‘friends’ discharged from psychiatric hospital into residential care.

“Through developing effective relationships and listening to their voice, concerns and aspirations, I learned so much about their tremendous resilience to overcome difficulties. I admired their courage, but also came to appreciate the damaging stigma attached to their psychiatric labels.”

Conclusion

“Recovery is possible for individuals, cities and countries. It is possible to remove barriers to what can appear like impossible situations, by using **cost-effective accelerated methods**, cutting edge research and alternative solutions, incredibly it is possible to create dynamic shifts in individual’s lives.”

[The researcher, agrees with John, however, has to add, “That first, we do no harm” and apply the old adage, ‘prevention is always better than cure’.]

John, further concludes: Effective trans-disciplinary research dialogues between education, health and social services need to take place, as well as a more user-led approach to research, which will result in the effective networking and overlapping of shared skills, expertise and knowledge. As Wellington et al (2005) state, “Cutting edge research is still the key rationale for any study.” (Wellington, 2005)

In order to lead effective transformative practice there needs to be a willingness to reach into people’s lives, listen and collaborate with them in order to drive a process of reform that will not only transform lives, but transform communities, creating a better future for all our children. Therefore, it is my vision to produce cutting edge multi-disciplinary research that challenges institutions, inspires changes in Government policy, through empowering ordinary people out of their hopeless situations of extreme poverty and to spearhead an effective positive transformation throughout society.

As Shirky (2008) writes, “When people care enough, they can come together and accomplish things of a scope and longevity that was previously impossible"

Everyone knows that achievement and the right environment floods the body with 'feel good' endorphins and enables people to build resilience to recover quicker. However, educational failure and toxic environments which reinforce failure causing damage to mental health, social inequality and inescapable poverty.

However, through engaging with all age service-users across the many different sectors, inside and outside traditional systems, I know that reflective, evidence-based multidisciplinary practice, along with user led voice and solution based practice evidently makes a real difference to people in difficult situations.

I believe that when people care enough and work tenaciously together, they can achieve that what was once thought impossible.

As Foucault (1980) states, "Power exists only in action."

THE HERE AND NOW - DID THE UK SET OUT TO ACHIEVE ITS MENTAL HEALTH VISION FOR 2015?
THE RESEARCHER HIGHLIGHTS THE 2005 VISION

The Sainsbury Centre for Mental Health
THE FUTURE OF MENTAL HEALTH: A VISION FOR 2015

2006

[The researcher's summation and analogy can be found on page 202, which highlights the current (2017) state of affairs, which is two years on from, The Future of Mental Health: A Vision for 2015 – Have we achieved this vision as set out below?

The research, evidence and data, show a slow and gradual acceptance of Mental Health, in the modern evolving era. The pace of acceptance and or the strategies/policies that are used to accept, (MH) are still unacceptable; two years to any child, can be compared to around eight years of an adult's life. Nothing has changed, except for a forced acknowledgement of Mental Health and its associated conditions, as recommended by the UN to the UK.]

The Local Government Association, the NHS Confederation, the Sainsbury Centre for Mental Health (SCMH) and the Association of Directors of Social Services have worked together over the past year to produce a vision of what mental health will be like 10 years from now. The project aimed to set out the best-case scenario, based on where we are now, of what it will be like to experience mental health problems in 2015.

The Vision for 2015

By 2015, mental wellbeing will be a concern of all public services. Undoubtedly there will still be people who live with debilitating mental health conditions, but the focus of public services will be on mental wellbeing rather than on mental ill health. The balance of power will no longer be so much with the system, but instead there will be more of an equal partnership between services and the individual who uses, or even chooses, them.

Schools will include emotional literacy in the curricula and will support students experiencing problems. Employers will compete to become 'Wellbeing Workplaces' which demonstrate good practice in supporting staff who experience problems and in positively recruiting those who have had mental health conditions. Mental health services will be integrated into ordinary health and other services: in libraries, GP surgeries and schools.

Current policy developments

A number of current and forthcoming policy developments form an important starting point to the next 10 years for mental health: an integrated community health and social care White Paper will be published. It will cover all aspects of care that people need in the community. It is likely to focus on providing services closer to people's homes or workplaces, bringing health and care services together, meeting people's needs at different stages of their lives, using new technologies, helping people to help themselves and involving people in shaping local services.

The Government has indicated that further work on social care will take place outside the White Paper including links to Derek Wanless' spending report for the King's Fund, due in Spring 2006, and reports on Department of Health (DH) pilots on individual budgets, culminating in a submission to the Treasury's Spending Review in 2007.

The Government has described the strategic agenda to bring together health and local government as "a marriage, not a treaty", promising "reform and improvement on the ground" (Byrne, 2005). It has committed the Care Services Improvement Partnership (CSIP), which now incorporates the National Institute for Mental Health in England (NIMHE), to work with the Local Government Improvement and Development Agency (IDeA) to develop the first joined-up national improvement strategy for adult social care.

Mental health services in 2015

Our vision for mental health in 2015 includes some far-reaching changes to the way services are managed and delivered. This section sets out some of the main changes that are required to achieve the vision. It focuses on services for people of working age. *Those services for children and older adults face many similar challenges but also very specific issues to which this paper cannot do justice*.

Mental health promotion

At the heart of our vision for 2015 is the premise that the focus of services will be shifting from mental health care to promoting mental wellbeing. Promoting mental wellbeing has, to date, been low down the policy agenda. The Government's '*Choosing Health' W*hite Paper (DH, 2004) made passing reference to mental health promotion, promising to work on improving mental health "because mental wellbeing is crucial to good physical health and making healthy choices; because stress is the commonest reported cause of sickness absence and a major cause of incapacity; and because mental ill health can lead to suicide". Yet there was no commitment to how this will be achieved.

Investing more in mental health promotion was one of the priorities listed in the Department of Health's five-year review of the NSF (DH, 2004). Mental wellbeing must be put on the agenda of schools if we are to see a new generation of emotionally-aware young adults in 2015.

While most school age children learn about emotional health and wellbeing as part of the Personal, Social and Health Education programme, there is no requirement on schools to include mental health in this curriculum. Education in social, emotional and behavioural skills is being piloted in some primary schools and many voluntary sector organisations are actively working in education.

[*Mental health promotion also needs to become a mainstream part of the role of local authorities*.]

Choice

Local authorities are already able to offer people direct payments for social care. The social care green paper (DH, 2005b) made it clear that greater use of direct payments will be encouraged in future and that individual budgets will be developed as an alternative for those unable or unwilling to hold their own budgets themselves. This can be developed by local authorities immediately.

[The researcher at this point interjects by stating: The above report; '*The Future of Mental Health, A Vision for 2015*', delivers coherent evidence, however it is the researchers own specific analysis and experiences that is completely the opposite of what this Vision has tried to deliver. For example: Social Services took 8 years, 11 months and 3 days to award Bastian Willicott, his Direct Payments for respite carer, so as to allow Bastian's mother a 4 hour break every week from her role has a 24/7/365 primary carer.

Social Services stated: "We didn't award the direct payment sooner as we didn't have the information", despite them having all of Bastian's records since May 2008; they then subsequently blamed the Education Department for keeping all of Bastian's records. However it was only until Janet Willicott (mother to Bastian), had cited the various specific legislations, that Social Services (Disabled Children's Team) should have followed in their assessments, but failed to do, did they finally concede by admitting, that Bastian was indeed suitable to be assessed and that he should have been awarded Direct Payments for his care. (No apology was ever received.)]

Care planning should also be targeted as an immediate priority for improvement. The Care Programme Approach can be an effective method of involving people in making decisions about their care and ensuring their full range of needs are addressed. Ensuring services across the country implement a comprehensive CPA system is an important task. In its response to the Government *Independence, Wellbeing and Choice* consultation when people choose to take control of their own care, they need support and advice.

It also needs to be considered what will happen when an individual's choices do not have the desired outcome and they end up needing different help. Will they be penalised for having made the 'wrong' choice, or will it be recognised that in the current system patients are often treated in many different ways until the 'right' solution is found?

Care plans, advocates and 'navigators' Every person in secondary mental health services should currently have a care plan, setting out what care, treatment and support they require. This is established under the Care Programme Approach (CPA), introduced in 1990. A good care plan is the key to integrating health and social services and can ensure that an individual's mental health and social needs are met.

By 2015 not only should everyone have a comprehensive, tailored care plan and be receiving the services stipulated in it, but they should have taken the lead in determining how they want their needs met.

[At the time of editing, (May 2017) – the UK Collective SEND Populace, all agree, that the facts are otherwise, SEND Needs are not being met, and with a £3 Million Education budget cut, it will get worse, which can be measured by the high SENDist Appeals uptake statistics.]

Discrimination

The prejudices attached to mental ill health are most problematic when they lead to individuals experiencing discrimination in their everyday life. From being denied job opportunities to being harassed in their neighbourhoods, people with mental health conditions complain of frequent discrimination. Recent legislation has improved the rights of people with mental health conditions to seek redress when they face discrimination.

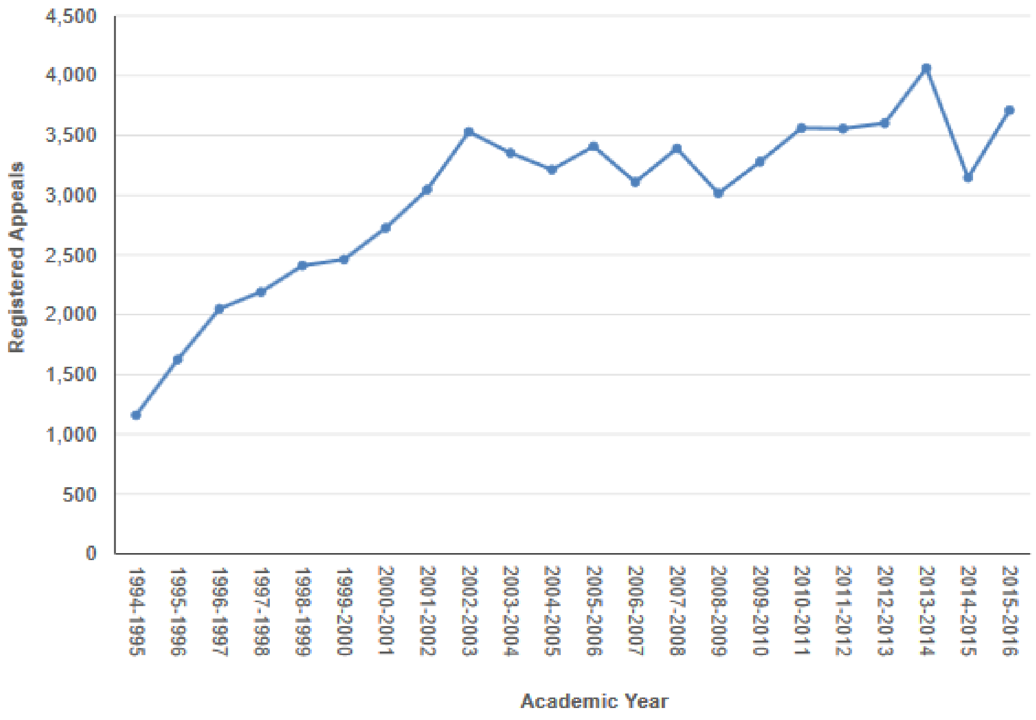
Schools

The National Healthy School Standard, jointly funded by the Department of Health and the Department for Education and Skills (DfES), aims to improve standards of health and education, to promote social inclusion and to tackle health inequalities. While the Government aims for half of schools to meet the criteria of the National Healthy Schools Programme by 2006, with the rest working towards Healthy School status by 2009, mental wellbeing is not among the criteria of this programme. Putting this right would be a major step towards creating a mentally healthy population in the coming decades. By 2015, mental wellbeing should be a major concern for schools, from dedicated classroom time to the overall approach of the school towards its pupils and staff.

[UNICEF League Table of Child Wellbeing – {Innocenti Report Card 11} – AYPH – KEY DATA on Adolescence 2015 –

The United Kingdom is still ranked at 16/29 for Child Emotional and Mental Wellbeing)) 2015, as per UNICEF Data 2013. The Data is clear – nothing has changed except for marginal shifts in the ‘acceptance of Mental and Emotional Health’- Willicott, J (2017)]

Figure 24: Registered appeals to the SEN Tribunal, September 1994 to August 2016



Graph 1. SEND Tribunal Statistics reflecting an 18% Increase since 2014

<u>What has driven ‘The Rise’</u>

There are a number of factors that could have contributed to the overall increase in SEN appeals between 1994 and 2016. These include:

- Greater understanding of special educational needs
- More provision of services
- Parents more willing to challenge local authorities

- Stronger push to keep children with special educational needs in mainstream schools.

In the academic year 2015 – 2016 HMCTS tribunals recorded 3,712 registered appeals in relation to SEND, up 18% when compared to 2014-15 when the new legislation was introduced.

What do we do next?

The agenda set out in the Sainsbury's Centre – Mental Health Vision 2015, is **and was** very ambitious. It represents our vision of what mental health could be like in 2015 in the best circumstances. But it is realistic if we start now. Among the key recommendations that can begin immediately, and which will get the UK on the right track are:

Developing more accessible services

Extending the availability of psychological therapies to people with a range of mental health conditions and developing intermediate mental health care teams.

Building up the mental health workforce

Putting in place, *strategic approaches* to workforce planning and seeking to untapped resources of future staff.

Pursuing race equality

Full implementation of the Delivering Race Equality action plan, for example giving community development workers the freedom they need to make real changes locally.

Supporting carers

Implementing the Carers (Equal Opportunities) Act 2004, through which carers' assessments must now include a consideration of whether the carer works or wishes to work or participate in any education, training or leisure activity.

Piloting individual budgets

The recent creation of 10 sites for piloting individual budgets should be the first step towards making these much more widely available.

Better care planning

Ensuring services across the country implement a comprehensive CPA system.

Investing in service user groups

Commissioners, PCTs and local authorities should ensure there is investment in developing and sustaining networks of people who use services and their carers at a local level. This is needed most urgently among Black and minority ethnic communities.

Conclusion

Our Vision for 2015 is for mental wellbeing to be on the agenda of all public services. Among the major developments we believe are achievable by 2015 are:

- All schools will promote mental wellbeing
- Employers will compete to become ‘wellbeing workplaces’
- People seeing their GP with a mental health problem will have a range of effective treatment options
- Mental health services will be integrated into ordinary health and public buildings: GP surgeries, libraries and schools

PROSPECTIVE LINKS BETWEEN SOCIAL ANXIETY AND ADOLESCENT PEER RELATIONS

Maria Tillfors et.al

2012

Links between peer relations and social anxiety

An elevated level of social novelty during adolescence should make adolescents with social fears more sensitive to interpret peer behaviours as threatening. This may exaggerate the social anxiety over time. Further, you could expect that low levels of peer acceptance, being victimized and low relationship quality, especially relationship negativity, should increase negative expectations in future social situations, and hence elevate the social anxiety over time.

However, being victimized could also through evoking both intense negative emotions in the situation as well as high levels of worry in anticipation of the next social situation be expected to contribute to increased levels of later social anxiety in a unique way.

Links between social anxiety and peer relations

As high levels of social anxiety might increase the use of self-protective behaviors social anxiety should predict less popularity among peers, increases in peer victimization, and lower relationship quality.

Collectively our findings suggest that peers seem to play a significant role for adolescent mental health and social anxiety seems to interfere with healthy peer relations. Importantly, developmental pathways for social anxiety seem to differ for adolescent females and males.

PEER RELATIONS AND THE UNDERSTANDING OF FAUX PAS: LONGITUDINAL EVIDENCE FOR BIDIRECTIONAL ASSOCIATIONS, CHILD DEVELOPMENT

Robin Banerjee et al.

2011

Children’s social understanding has been a major focus of developmental psychology research over the last 25 years. Work on this topic has revealed reliable developmental progressions in children’s understanding of mental states, such as beliefs, emotions, intentions, and desires, which are clearly pertinent to human social behaviour (e.g., Flavell, 2004; Hughes & Leekam, 2004). Moreover, there is dramatic evidence of individual differences in this kind of “theory-of-mind” (ToM) understanding.

Research with individuals on the autistic spectrum has suggested that significant social impairments can be linked to difficulties in reasoning about mental states (e.g., Baron-Cohen, 1995; Happé, 1994, 1995). Such evidence supports the intuitively appealing notion that individual differences in social understanding are connected with children’s social interactions and relationships.

The precise details of social understanding implicated in a child’s perspective-taking performance often remained opaque in this work, but one important feature of the early conceptualizations of developments in perspective taking was that children were not assumed to undergo a seismic shift from no understanding to full understanding of others’ perspectives.

Unfortunately, in the years that followed, children’s gradually increasing sophistication in understanding others’ mental states was to a large extent overshadowed by the focus on a single transition in recognizing the representational nature of belief states as measured by the false belief task (Chandler, 2001). Now, however, we can return to the notion of a complex and multifaceted model of social understanding, emerging within the context of children’s interactions with social partners in order to understand why the faux pas task may serve as an important correlate of real-life peer relations.

These observations fall neatly in line with other research suggesting that aspects of children’s interpersonal experiences play a role in the development of their social understanding. In past research, this has been most convincingly demonstrated within the family context. As noted earlier, both general aspects of the mother–child relationship and specific features such as use of mental-state language have been implicated in the development of ToM skills (e.g., Dunn et al., 1991; Meins et al., 2002; Ruffman, Perner, & Parkin, 1999; Ruffman et al., 2002). Similarly, a number of studies have highlighted the role of siblings in this area of social-cognitive development (McAlister & Peterson, 2007; Ruffman et al., 1998). The study builds on the evidence by showing how the peer relations context may be critical for acquiring advanced forms of mental-state reasoning.

Implications for Models of Social-Cognitive Development

The above study had important implications for our theoretical models of social-cognitive development, and in particular for our formulations of social-cognitive development beyond the age of 5 years. Perhaps most significantly, it shows that peer relations constitute a critical context for the development of social understanding, with peer rejection not only shaping, but also being shaped by, children's reasoning about situations.

As Banerjee et, al. 2011, states in the above complex social paper, peer relations do constitute a critical context for developing a social understanding – therefore were Bastian placed in the oppugning school – his awareness of self and social understanding by virtue of his 'institution placement ' could be affected. It is there in Bastian's best interests to have a continuum of environment to ensure that his wellbeing and mental health is at the forefront of any schooling placement.

[The recognition of disabled children as full human beings is only comprehensively achieved by adopting the social model of disability. This perspective separates out the impairment (the characteristics of someone's body or mind) from the disabling barriers (the way society and individuals react to impairment).

A disability rights perspective, informed by the social model of disability, asserts that it is not impairment which determines quality of life but disabling attitudes and unequal access to education, communication, employment, leisure activities, housing, health care and so on.

This is why the disabled people's movement uses the term "disabled children" rather than "children with disabilities". The former term refers to what society does to children with impairments (i.e. it disables them by prejudicial attitudes and unequal access), while the later term uses the word "disabilities" to mean impairments and thus defines them by what their bodies or minds cannot do. Within the social model of disability, the word "disability" refers to oppression and disenabling factors, not to impairment. (Morris 1998)]

In order to answer the Sainsbury Centre Future of Mental Health Vision 2015 – Has the UK achieved its 2015 Visionary Goals for Mental Health?

Perhaps the researcher could have a biased or skewed view – however the data reads as such: (Question delivered in UK Parliament February 2015 and answered by Normal Lamb – The Minister of State, Department of Health

Norman Lamb Minister of State, Department of Health

The information is in the table:

Year	2009-10	2010-11	2011-12	2012-13	2013-14
A&E Attendances	8,358	9,328	11,614	13,655	17,278
FAEs	11,909	12,417	12,361	11,994	12,126

Table 1: Accident and Eemergency (A&E) in which the A&E diagnosis was 'psychiatric conditions'

The table shows both the number of attendances in accident and emergency (A&E) in which the A&E diagnosis was 'psychiatric conditions' and the number of Finished Admission Episodes (FAEs) in which the primary diagnosis was ‘mental and behavioural disorders’. - (UK: Parliament – February 2015)

The increase in Child Mental Health and Emotional Wellbeing incidences has increased, despite the UK pledging to addresses the critical issues.

Children and Young People's Mental Health - role of Education Inquiry

NAHT response to Health Committee inquiry

The Health Committee launched an inquiry in December into the role of education in promoting emotional wellbeing in children and young people and preventing the development of mental health problems. This inquiry is specifically examining the role of education in promoting emotional wellbeing in children and young people and preventing the development of mental health problems.

Evidence submitted to the inquiry, including NAHT's response, has now been published.

In our response, we recognise the fundamental role that mental health plays in children's success and that poor mental health is a significant barrier to learning.

We go on to develop the following key points:

- NAHT believes that the vital role for schools is to contribute significantly to promoting good mental health and emotional wellbeing amongst pupils of all ages. The vast majority of schools already have protective factors in place to support pupil's mental health and engage with a wide variety of activities to promote and support good mental health and wellbeing.

- NAHT supports the introduction of a statutory framework for PSHE for all pupils in all schools to enable pupils to understand and explore the issues around mental health and to protect children in the digital world by teaching them about their rights and responsibilities online.

- In order for staff in schools to promote and support good mental health in their pupils, teachers and school leaders must be supported to maintain their own mental health. Mental health problems are frequently highlighted as a concern in the teaching profession.

- A second crucial role for schools is in the early identification of pupils suffering from mental health problems. Teachers and school leaders must be to be empowered to play this vital role in the system.

- There can be no expectation on any school to provide health and social care services funded from the school budget, unless additional secure funding is provided for schools to be able to deliver these to support the unmet mental health needs of pupils.

- NAHT seeks a commitment to invest further in health and social care services, including CAMHS, to increase the capacity to meet the growing demand from schools and pupils for their services and to reduce waiting times for this support.

- NAHT believes that all school staff should receive high quality CPD throughout their career so that they can promote good mental health and emotional wellbeing, are well placed to identify emerging mental health needs of pupils and can support and manage pupils with mental health needs in the classroom and school environment.

(Page Published: 23/02/2017)

In Summary – Educational institutions are in agreement with the notion –'unless the Government allows and allocates a budget – no amount of 'scape goating' will absolve Local Authorities their very real duty to provide for said; as school institutions are already scraping the barrel to stay afloat. Mental Health is reaching breaking point.

[Therefore, in the case of [Bastian Willicott v UK] it is clear – 'first do no harm' – 'prevention is better than cure' – and allow him a 'Voice and Choice, after all he, is by virtue of birth, allowed his humanness.]

AUTISM AS AN ADAPTIVE COMMON VARIANT PATHWAY FOR HUMAN BRAIN DEVELOPMENT

Developmental Cognitive Neuroscience

Mark H Johnson

2016

[For the purposes of this report, the researcher uses Johnson’s article so as to articulate neuroplasticity development through an environment that correlates to the child’s voice and reasoning.]

While research on focal perinatal lesions has provided evidence for recovery of function, much less is known about processes of brain adaptation resulting from mild but widespread disturbances to neural processing over the early years (such as alterations in synaptic efficiency). Rather than being viewed as a direct behavioural consequence of life-long neural dysfunction, I propose that autism is best viewed as the end result of engaging adaptive processes during a sensitive period. From this perspective, autism is not appropriately described as a disorder of neurodevelopment, but rather as an adaptive common variant pathway of human functional brain development.

A variety of different pre and perinatal factors can lead to diffuse and widespread atypicalities in neural processing during the first years of life. The consequences of such events for later development are much less well understood then are the effects of more punctate and focal damage, such as those arising from discrete perinatal neurovascular events. In the latter case, substantive evidence supports the triggering of adaptive and compensatory processes within remaining intact tissue that help restore, to the extent possible, the typical trajectory of postnatal human brain development.

However, much less consideration has been given to processes of adaptation engaged following diffuse and widespread differences in the fidelity of signal processing, or in the homeostatic neurochemistry related to the synapse. In this paper I further develop the idea that some behaviourally-defined clinical phenotypes, such as autism, are the developmental consequence of natural chain of adaptive responses to such atypicalities in early life neural processing.

A variety of homeostatic processes in the brain ensure optimal balances in key factors such as excitation/inhibition (E/I) balance, and neurotransmitter balance (Turrigiano, 2011). In contrast to some well-studied local cellular and molecular homeostatic mechanisms that can restore local adaptive balance, we know considerably less about the whole brain and neural systems level adaptive processes, and even less about their compensatory responses in the face of altered signal processing at the synapse. This gap in our knowledge may be critical given that common developmental disorders, such as autism and ADHD, are known to result from both intrinsic and environmental factors; in other words, the way a particular brain adapts during ontogeny to its individual social and physical environment. **Furthermore, the way an environment is sampled and perceived early in life itself depends on the specific properties of the brain processing it. Thus, the "effective environment" experienced by some infants may be different simply due to their own particular neural processing limitations.**

In a recent paper (Johnson) speculated that the diagnostic behavioural symptoms of autism are the result of processes of early life adaptation in response to atypical neural signal processing, potentially at the synapse (Johnson et al., 2015). This sub-optimal quality signal processing may be caused by genetic or environmental effects, sensory limitations, or most often by combinations of factors.

Nevertheless, the adaptive response of the developmental trajectory of the human brain will be similar, and the end result of this trajectory, we argued, is the autism diagnostic behavioural phenotype. From this perspective, the coherence of the clinical syndrome originates in the brain's unitary response to different kinds of altered synaptic processing, possibly reflected in signal-to-noise ratio.

Johnson proposed that a series of compensatory and adaptive processes trigger an alternative trajectory of subsequent development, resulting in the majority of the behavioural phenotype associated with an autism diagnosis. By analogy, a single systemic adaptive response such as elevated body temperature (fever) can be triggered by many different causal factors (bacterial, viral, etc.). According to this view, autism should not be described as a **disorder** of neurodevelopment; but rather as a perfectly ordered developmental response in the face of an unusual starting state.

Whole brain adaptation

Processes in the brain can be observed at multiple levels of organization from molecular to cellular to large-scale systems. Within neuroscience, processes of adaptation have generally been studied at molecular and cellular levels, with less focus on how large-scale neural pathways and systems can compensate for either focal or diffuse disturbances. Two reasons for focusing on this 'whole brain' level of description of the nervous system are: (1) to fully understand processes of ontogenetic adaptation we need to consider the whole brain, where evidence shows that distant neural systems and regions can adjust to compensate for poor functioning or damage elsewhere, and (2) common developmental disorders are associated with widespread changes in the functioning of large-scale neural networks, even though these often have multiple different underlying molecular and cellular correlates (Johnson, 2015).

Thus, in linking the brain to clinical diagnostic behaviours in developmental psychopathology we need to bridge our understanding with models of whole brain systems function and dysfunction.

In parallel, while the concept of adaptation has had multiple definitions within developmental cognitive neuroscience, these have generally been taken to refer to neural processes or behaviours that are shaped by recurrent problems that faced ancestral populations (e.g., see Bjorklund, 2015). My use of the term is as applied to the restoration of a homeostatic balance after a perturbation in individual development; in other words, **ontogenetic** rather than **phylogenetic** adaptation.

It is important to note that ontogenetic brain adaptation does not necessarily lead to a typical outcome. In child psychiatry the concept of **resilience** is commonly used to refer to the extent to which an individual withstands or recovers from early disturbance of their developmental trajectory to achieve normality (Cicchetti, 2013; Cicchetti and Curtis, 2007; Masten, 2007).

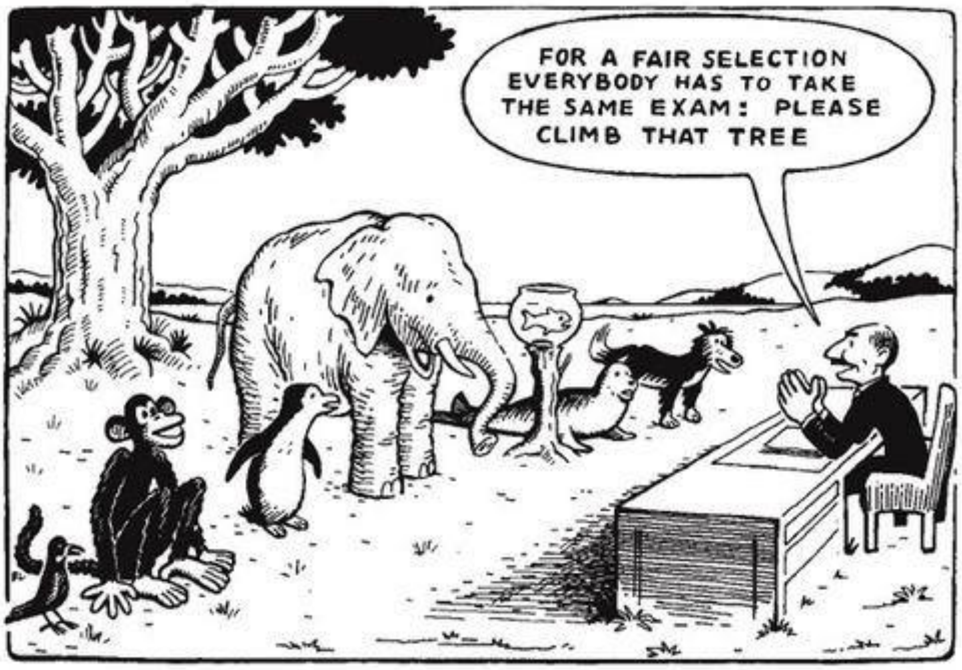
However, **ontogentic adaptation** refers to a broader class of processes in which a given individual's brain maximizes its fit to the environment in ways that may, or may not; result in a neurotypical behavioural phenotype. Computational models of the cerebral cortex suggest that a range of different starting state disturbances result in one of a small number of atypical outcome phenotypes; a many-to-few mapping (see Oliver et al., 2000).

In other words, the "effective environment" experienced by a developing brain will partly result selection of a sensory environment that best suits its own processing capacities.

These are all examples of ontogenetic niche construction – an individual brain selecting those aspects of its environment which it is best suited to process, and generating behaviours to maximize sensory information that can be processed.

Conclusions and future directions

Johnson addressed some key questions raised by a perspective on autism that views it as an alternative trajectory of human neural and behavioural development, and discussed how general factors may drive the alternative pathway to autism, and give rise to its uneven behavioural profile. I also discussed analyses of whole-brain connectivity that may underlie the adjustments in whole brain systems to accommodate early differences in synaptic processing efficiency.



Graphic: Howard Earl Gardner's (1943-) work in *"Frames of Mind. The theory of multiple intelligences"*

"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid." "Education is what remains after one has forgotten what one has learned in school" and "It is a miracle that curiosity survives formal education" and finally "The only thing that interferes with my learning is my education". - Albert Einstein

[Therefore – it is clear that the brain will plasticise, develop and mature when best placed in an environment suited to the individuals own needs. Change the Environment and not the Child.]

UNICEF – IT'S ABOUT ABILITY – AN EXPLANATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 7: Children with Disabilities

'Governments agree to take every possible action so that children with disabilities can enjoy all human rights and freedoms equally with other children. They also agree to make sure that children with disabilities can express their views freely on all things that affect them. ***What is best for each child should always be considered first****.*

Boys and girls with disabilities have the same rights as all children. For example, every child has the right to go to school, to play and be protected from violence, and ***to be involved in decisions that affect him or her****. Governments must provide the Information and support necessary for children with disabilities to realise this right'*

CONCLUSION AND FINAL ANALYSIS
NORMAL LIKE ME

Did the UK Government achieve its Vision on Mental Health for 2015? Is the UK really implementing its policies and strategies, and lastly does the UK comply with legislation?

THE KEY

The Key provides impartial, trusted leadership and management support to schools in England and Wales. At the heart of everything we do is a commitment to supporting schools in delivering better outcomes for young people. The Key was set up in 2007 to meet these needs. Fergal Rocher led the organisation from its inception - during the initial DfE pilot phase through to its national roll out to become a completely independent membership organisation.

The Key (Independent Research Organisation for Education') delivers its verdict (June 2016).

> *Fergal Roche, chief executive of The Key, said: "A year on from major reforms to the national system for SEND provision, these findings represent an important wake-up call from school leaders.*
>
> *"Schools need adequate funding and a holistic, well-co-ordinated and resourced system of support behind them to provide effectively for children with SEND."*
>
> *Cllr Roy Perry, chairman of the Local Government Association's children and young people board, said: "We were clear with the Department for Education at the time that implementing the SEND reforms in the Children and Families Bill was significantly underfunded by the government and this has been borne out in reality*."

It is clear and evident, that the UK Government and its Local Authorities are failing to support their vulnerable who are the very heart of their future, by undercutting budgets, providing lacklustre provisions failing to take any accountability in so far that the UK Government are willing to unlawfully abuse due process as well as to extrapolate funds to halt providing educational provision by its very own legal obligation.

The Normal-Like-Me Researcher concludes; this report overview is based on a holistic culmination of comparable literature; comprising, Neurology, Biology, Biomedicine, Neuroscience, Psychology, Educational Pathways, Paediatric Medicine, Educational Law, Sociology, Public Health, Environmental Health, International Law and Human Rights Laws. This report is to be used as a research guidance document.

In the case of [B Willicott v United Kingdom 17275/15-39415/16- ECHR], we the researchers as a society, or indeed as a global researching community, haven't yet reached the pinnacle in understanding human neurology. The complexity of the human brain is as diverse as the world itself; particularly when trying to understand, compare or further research rare diseases; however and more importantly, it is the Government who fails to listen to the professionals, experts and experienced parents, who, were if given the chance, could pave a way forward for the rare diseased, so as to avoid costly and very lengthy legal processes which severely impact the lives of those who are affected.

No one size fits all, we as a species [homo-sapient], are all individually unique, therefore trying to place individuals into 'indifferent same size fits all environments' could and does adversely affect their individual psychological, mental and emotional well-being, resulting in what could be a lifelong discourse of irreparable damage.

It is therefore deemed illogical to state that any Government or indeed Local Authority can and does have a distinct understanding of a child or person's needs, by simply using a '20 minute observation' and or an hour's educational psychological assessment, to underpin its case when placing a child into a schooling environment or assessing them when arranging suitable schooling placements.

It is imperative that Governments' listen to parental expertise, for it is this very mechanism that would allow Governments to save misappropriation of taxes rather than to frivolously waste funds on nonchalant legal outcomes, which intern serve no one, except for legal representatives.

$SETD_5$ is clearly defined as an extremely rare and highly complex condition by the medical and neuro-scientific professional community. The empirical evidence as laid out in this case has yet to be further analysed, based on the rarity of said. Therefore those who act with governmental powers on behalf of a LA's with little or no understanding of the D5 receptor and it's neuro-functioning role, cannot be deemed fit to be in the position of legally defining educational and emotional needs of an individual with this condition, which directly contradicts those of numerous top professional neuroscientists.

This case is axiomatic in so far as to say the UK Government has failed to apply its Human Rights Act 1998, European Human Rights Law 1950, Rare Disease Strategy 2010, inadequately complying to UNITED NATIONS Millennium Development Goals 2000, International Law under the UNITED NATIONS – UNICEF – UNCRC - Child Rights Charter 1989 'The Voice of the Child', as well as the Social Sustainable Development Goals 2016.

“History will judge us by the difference we make in the everyday lives of children” – Nelson Rolihlahla Mandela

“It is not in our best interests to act upon our moral and ethical values as citizens of one species in so far as to take full accountability for those who struggle to have their voice heard in our ever-changing world?” Janet Hilary Willicott (2016)

The Researcher would like to express her thanks to Diane Montgomery (2003) (Gifted & Talented Children with Special Education Needs) for taking the time at length to discuss the concept “*Double Exceptionality*” which adequately describes ‘Bastian the Enigma Boy’, for he truly is an enigma, a double exceptionality and a contradiction in terms; truly unique and wholeheartedly individual.

The researcher is indebted to Gail John (2014 & 2016) for her invaluable work and research processes as well as her continued work in the area of Neuro-Diversity and safeguarding children of all abilities. Her evidence in child led research, linking Neuro-science within educational processes is clear; whereby she embraces and mixes the ‘medical model evidence based research findings’ within a ‘traditional social model environment’ to increase educational standards, thus improving dopamine levels, so as to improve and or ameliorating the lives of those who struggle and live with Mental Health conditions, thus embracing and combining Neuro-science with Educational outcome. John’s research was presented at the Neuro-Science and Education Conference 2013 to great acclaim.

It is clear by this comprehensive overview, that the UK, still have an extensive way to go in bridging the current educational void when it comes to understanding SEND. The researcher fears that it will take at least a further two to three generations will lose out, before any real long-lasting change take place. Who does the ‘Layman turn to, when the very same Government who is there to protect them, fails to take accountability?

THE KIDS RIGHTS INDEX - 2017
KidsRights Foundation in Cooperation with Erasmus School of Economics and The International Institute of Social Studies

May 2017

The researcher hereby underpins this entire Independent, Theoretical and Empirical Reference Guide for all SEND Spectrum Children on the below KidsRights Index 2017 – ***The Child's Voice must be heard***.

In line with Child's Rights Convention, The United Nations Committee on the Rights of the Child - EVIDENTIAL FINDINGS and CURRENT DATA 2017

About KidsRights

KidsRights is an international non-governmental organization that promotes the wellbeing of very vulnerable children across the world and advocates the realisation of their rights. KidsRights strives for a world where all children have access to their rights and are empowered to realise the great potential, they carry within them. KidsRights sees children as 'changemakers' who have the power to move the world and facilitates them in voicing their opinions and taking action in order to bring about change.

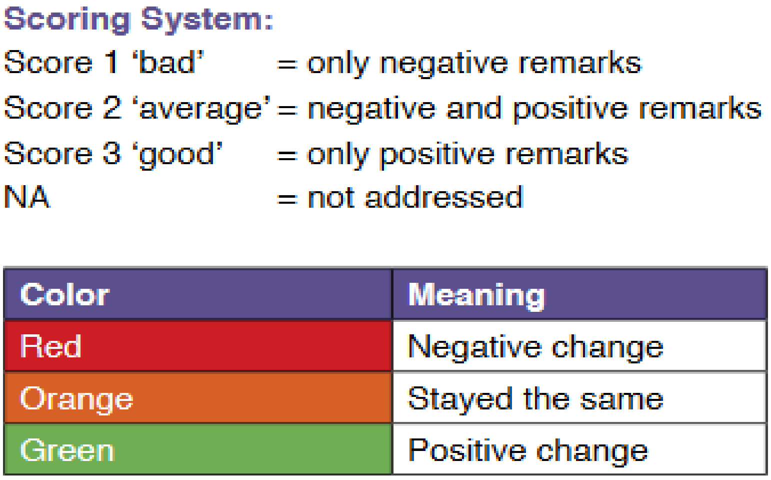
KidsRights supports children by commanding global attention for the realisation of children's rights and acting as a catalyst to ignite change, together with children and youth. This advocacy is supported with research and action. The foundation also finances local projects aimed at directly improving the rights of vulnerable children and stimulating child participation and changemaking by youths.

The KidsRights Index: why it matters

The Convention on the Rights of the Child is ratified by all of the world's states but one: The United States of America. The adoption of the Convention 26 years ago marked a crucial step in improving children's rights worldwide. However, there is still a considerable gap between the good intentions of policymakers and the actual effects policy has on the everyday lives of children. Take the UN Sustainable Development Goals, for example. The UN General Assembly adopted the Sustainable Development Goals (SDGs) in September 2015.

They show yet more concrete attention for the position of children than the earlier Millennium Development Goals did. The scale and ambition of the SDG agenda present unprecedented opportunities to truly improve the daily lives of children and youths. Although the Index is not a direct tool for monitoring performances of individual countries regarding the SDGs, it does provide crucial insights into what is being done and where countries need to do better to guarantee children's rights.

United Kingdom's record in the 2016 Concluding Observations shows on all six available indicators the lowest score (non-discrimination, best interests of the child, and respect for the views of the child, enabling legislation, budget and data). The score on best interests of the child stayed the same as it was in 2008. The score of 2016 on data improved from non-available to the lowest score. The scores on non-discrimination respect for the views of the child, enabling legislation and budget dropped from an average to the lowest score. The score on state-civil society cooperation dropped from the highest score to non-availability. With no score available on state-civil society cooperation, which was present in 2008, the completeness of the United Kingdom's scores deteriorated.

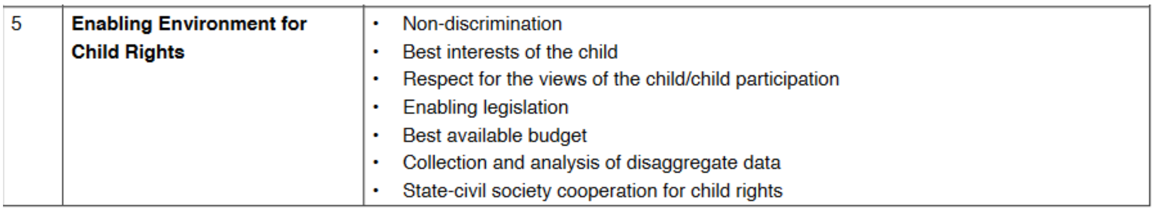


Scoring System:

Score 1 'bad' = only negative remarks
Score 2 'average' = negative and positive remarks
Score 3 'good' = only positive remarks
NA = not addressed

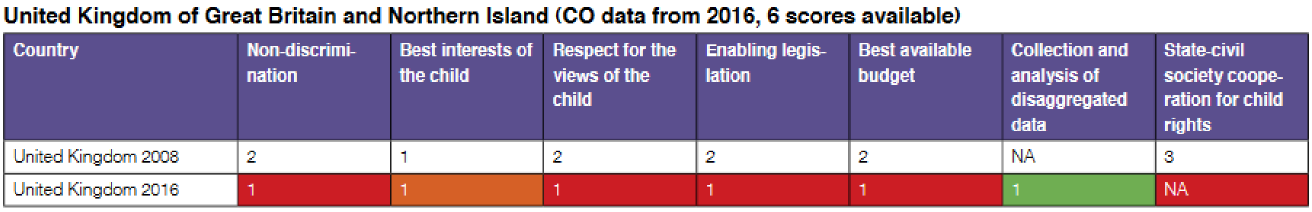
Color	Meaning
🟥 Red	Negative change
🟧 Orange	Stayed the same
🟩 Green	Positive change

Graphic: The Kids Rights – Scoring System



5	**Enabling Environment for Child Rights**	• Non-discrimination • Best interests of the child • Respect for the views of the child/child participation • Enabling legislation • Best available budget • Collection and analysis of disaggregate data • State-civil society cooperation for child rights

Graphic: The Kids Rights – Domain 5



United Kingdom of Great Britain and Northern Island (CO data from 2016, 6 scores available)

Country	Non-discrimi-nation	Best interests of the child	Respect for the views of the child	Enabling legis-lation	Best available budget	Collection and analysis of disaggregated data	State-civil society coope-ration for child rights
United Kingdom 2008	2	1	2	2	2	NA	3
United Kingdom 2016	🟥 1	🟧 1	🟥 1	🟥 1	🟥 1	🟩 1	🟥 NA

Graphic: The Kids Rights – UK Positioning and Scoring

The KidsRights Index pools data from two reputable sources:

1. Quantitative data published and regularly updated by UNICEF at www.data.unicef.org1

2. Qualitative data published by the UN Committee on the Rights of the Child in its detailed individual country reports (the so-called Concluding Observations) for all states that are parties to the UN Convention on the Rights of the Child.

The KidsRights Index makes these data more accessible to a broader audience, so as to encourage dialogue about children's rights. The Index covers five domains with a total of 23 indicators. It consolidates the most crucial general children's rights areas and implementation requirements of the CRC for which sufficient data is available.

The five domains are:
1. Right to Life
2. Right to Health
3. Right to Education
4. Right to Protection
5. Enabling Environment for Child Rights

The KidsRights Index provides an overview of country performance on each of the five domains and is a basis for making concrete recommendations to countries on how to improve. The KidsRights Index includes a total of 16 quantitative and 7 qualitative indicators which, when available, are systematically rated in the same way for all countries. Domain 5, the 'Enabling Environment for Child Rights' - or Child Rights Environment in short - is an important and unique domain within the KidsRights Index. It reveals the extent to which countries have operationalized the general principles of the CRC (non-discrimination; best interests of the child; respect for the views of the child/participation) and the extent to which there is a basic 'infrastructure' for making and implementing child rights policy, in the form of enabling national legislation; mobilization of the 'best available' budget; collection and analysis of disaggregated data; and state-civil society cooperation for child rights).

The scores on domain 5 are derived from the Concluding Observations adopted by the UN Committee on the Rights of the Child. These Concluding Observations finish off the state reporting procedure under the CRC and represent the Committee's views on the level of realization of children's rights in a particular country.

The scope for realising the full spectrum of children's rights is not only determined by income, or by level of economic or human development In line with CRC, the UN Committee on the Rights of the Child considers the implementation record of states parties to the Convention with a certain level of consideration for the development level and/or implementation capacity of those states parties. For example, according to article 4 of the CRC, states have to mobilize ‘the maximum extent of their available resources’. This may have different actual implications for some states as compared to others. For example, a highly developed country can be expected to mobilize more resources than a least developed country. Accordingly, in situations in which relatively limited means are available to implement the CRC, political will to genuinely prioritize children’s rights by allocating the maximum/best available budget can make a significant difference. Likewise, certain well-resourced countries might nevertheless have failed to adequately address discrimination of children or may not have been active on gathering disaggregated data on the situation of (particular groups of) children in that country. This explains why in certain situations perhaps rather unexpected scores may be obtained on the KidsRights Index.

Only one of the countries that were assessed by the CRC Committee in 2016 managed to obtain the maximum score of 3 (indicating the presentation of positive remarks only in the CRC Concluding Observations). Latvia scored the maximum score on enabling legislation.

In the KidsRights Index 2016 eight countries scored the maximum score (on enabling legislation and State-civil society cooperation).

This might be caused by the fact that the CRC Committee assesses a state more strictly over time (for example because previous Concluding Observations were not acted upon).

According to the CRC Committee, New Zealand (158th), the United Kingdom (156th) Italy (83rd) and Luxembourg (56th), for example, could do more to improve the enabling environment they have built for children’s rights. These wealthy countries should be able to invest more in children’s rights but fail to do so sufficiently striking differences Compared to the KidsRights Index 2016, the KidsRights Index 2017 leads to striking differences for 11 countries.

These 11 countries moved 25 positions or more in the overall ranking. Besides these 11 countries, two new countries were added to the KidsRights Index. For the first time, sufficient data was available on Nauru and Samoa to allow their inclusion in the KidsRights Index 2017. They entered the KidsRights Index at rank 89 (Nauru) and rank 52 (Samoa). Out of the 11 countries that show striking differences in the KidsRights Index 2017, 9 were subject to the CRC state reporting procedure in 2016 and thus received a new score for domain 5 ‘Enabling Environment for Child Rights’. Just deserve honourable mentions for having risen among the ranks significantly since last year’s Index.

These countries score relatively high as they have improved substantially in fostering an enabling environment for children's rights. To the contrary, the United Kingdom (11 to 156), New Zealand (45 -158), Slovakia (6 - 107), Saudi Arabia (80 - 144), Maldives (62 - 111) and Ireland (7 - 41) score remarkably poor compared to 2016 and are urged to do more to foster the rights of their youngest generation.

KidsRights Index 2016: countries falling short on children's rights - Maandag, Juni 13 2016

KidsRights, the international children's rights foundation, in collaboration with Erasmus University, has today published the KidsRights Index 2016. The Index is an annually updated global ranking that charts the extent to which countries worldwide adhere to and are equipped to improve the rights of children. This year's list underlines that, worldwide, countries are falling short on the implementation of the UN Convention on the Rights of the Child.

KidsRights urges all 163 countries analysed in the Index to increase efforts to combat discrimination against minority groups of children and youth especially. Vulnerable and marginalised children, including refugee children, migrant children, disabled children, street children and indigenous children are still widely discriminated against. Another area in need of improvement is the much-needed cooperation between the state and civil society, which is still underdeveloped in various countries. KidsRights is especially alarmed by the increased threats posed to the safety of children's rights defenders, journalists and civil society activists. In too many countries such practitioners are being harassed, threatened, abused or jailed.

Moreover, many countries fail in facilitating true child participation. Marc Dullaert, founder and chairman of the KidsRights Foundation urges countries to do more in this respect: "Not a single one of the 163 countries analysed in the Index achieved the highest possible score on child participation.

This means that the views of the 2.2 billion children on this planet are not being heard adequately regarding issues that affect them directly. KidsRights strongly urges all countries to increase efforts to ensure that the views of children are properly respected."

When taking a closer look especially at domain 5 'Enabling Environment for Child Rights', the KidsRights Index generates material for some notable conclusions.

1) *Worst scores on 'non-discrimination'*

All over de world groups of children are suffering from discrimination. They lack access to education and basic health care, and they are not given the same opportunities to develop themselves as other children. Unfortunately, there are no exceptions; none of the countries in the KidsRights Index receive 'good' scores on the non-discrimination indicator in domain 5. And even more worrisome, of all indicators in this domain, on average countries score worst on the principle of non-discrimination and 64 (out of 165) countries score 'bad' on non-discrimination.

Vulnerable and marginalised children such as girls, refugee children, migrant children, disabled children, street children or indigenous children especially continue to face discrimination in the societies they live in. In order for all children to fully enjoy their rights, it is absolutely crucial that countries ban discrimination of marginalised groups of children. Countries need to grant equal opportunities for all children to develop, go to school and have access to health care. Sustainable development can only happen with educated, safe and healthy children, who are able to grow up in inclusive, supportive and peaceful societies.

2) The principle of the 'best interests of the child' is nowhere fully implemented

According to the CRC, the best interests of the child should be a primary consideration in all actions concerning children, so that when decisions are taken about the child, they reflect what will serve the child best. On taking the best interests of the child at heart, there is not a country in the world that scores 'good', while 48 countries score 'bad', including Australia, Canada, Italy, Japan and the United Kingdom. All over the world decisions are taken about the child without considering the best interests of the child adequately, especially in cases where children are being separated from their parents or for migrant and refugee children. Judges and other professionals working for and with children should be trained on how the principle of the best interests of the child should be implemented in judicial and administrative decisions and other interventions.

3) Legislation should be improved

Of all indicators in domain 5, countries on average score best on enabling legislation. This shows that countries in general do have fairly appropriate legal frameworks that recognise and guarantee the rights of all children. This is a major achievement that has been stimulated by the Convention on the Rights of the Child. Unfortunately, for a lot of countries the level of implementation is low and gaps can still be identified where the rights of children are not sufficiently protected in legislation. States should enact enabling legislation for child rights and implement this legislation in all procedures. Laws and procedures should be in conformity with the CRC.

4) Countries allocate insufficient budget

Governments should allocate their best available budget to realize the rights of children. In 2017 none of the countries in the KidsRights Index scores ‘good’ on best available budget. 64 (out of 165) countries score ‘bad’ on best available budget. The latter include wealthy countries such as Denmark, the Netherlands and Sweden. Even more so, it is striking that, of all regions, the industrialised countries score relatively worst on best available budget. The Latin American and Caribbean region scores relatively the best.

These outcomes are partly explained by the fact that, as explained before according to the CRC (art. 4), states have to mobilize ‘the maximum extent of their available resources’. This may have different actual implications for some states as compared to others. For example, a highly developed country can be expected to mobilize more resources than a least developed country. Accordingly, in situations in which relatively limited means are available to implement the CRC, political will to genuinely prioritize children’s rights by allocating the maxim/best available budget can make a significant difference.

5) Participation of children is lacking behind

There is still a lot to achieve on the aspect of respecting the views of the child. At present, none of the countries in the KidsRights Index score ‘good’. This means that none of the 2.2 billion world’s children have their views fully heard on matters that affect them directly. 41 (out of 165) countries score ‘bad’ on child participation. Of all regions, the Asia and the Pacific region and the African region score worst on child participation.

Structurally engaging children and youth in decision-making processes affecting their lives is an important children’s right and should be implemented worldwide. Children are not mere beneficiaries of support; they can be agents of change. We need to get the views and ideas of children and youth and make them count. Only then shall they be able to hold their governments accountable. KidsRights Foundation in ooperation with the results of the KidsRights Index 2017 9 Countries therefore should take measures to implement legislation recognising the rights of the child to be heard in relevant legal and administrative proceedings and meaningful and empowered participation of all children should be promoted and implemented.

6) More data collection is crucial

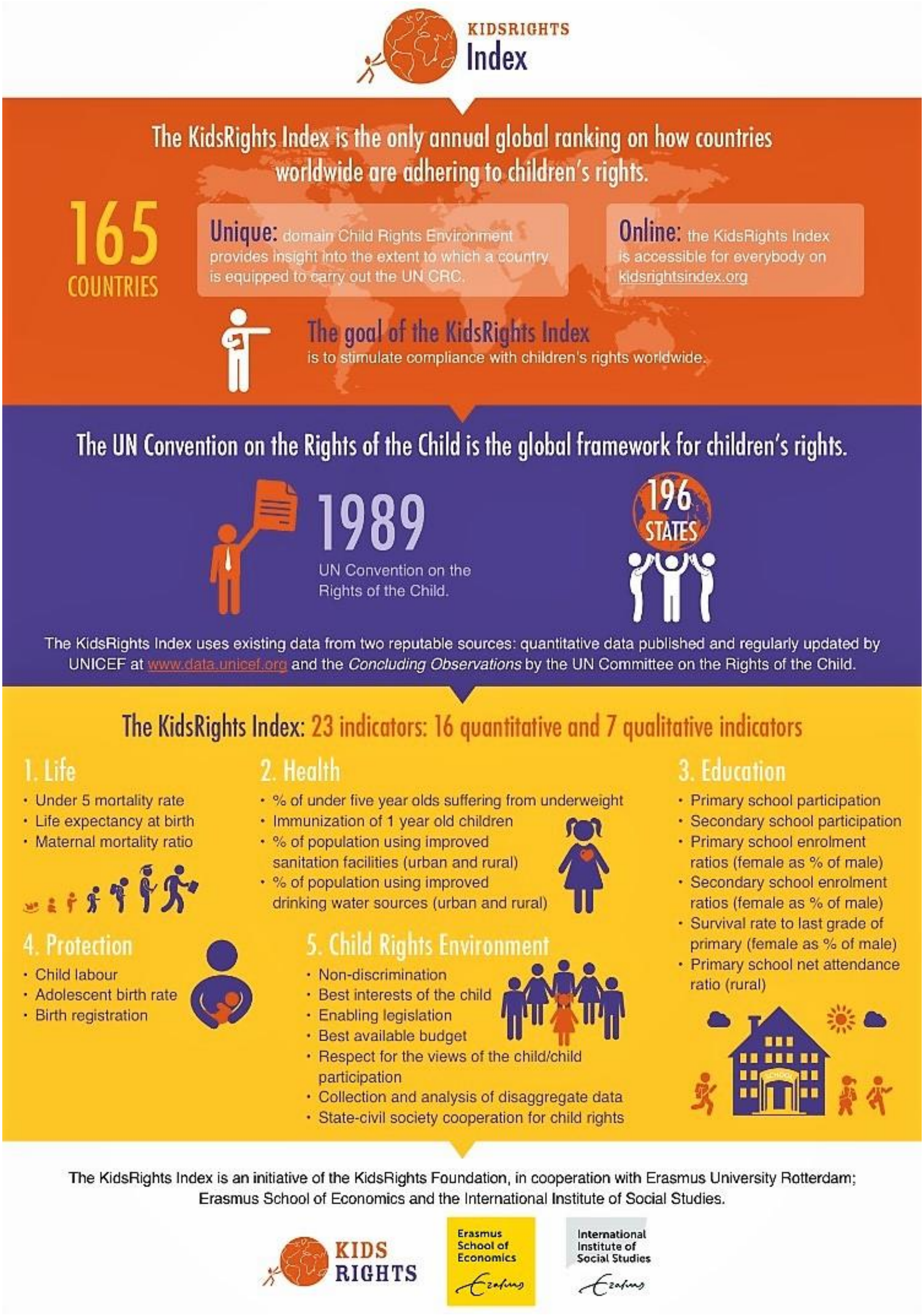
Disaggregated data, that is data collected on the situation of (particular groups of) children in a country, are important to be able to drive decisions on the development of children´s rights. Better collection and analysis of the data can assist in realizing and protecting the rights of all children as decisions can be taken on the specific needs of particular groups of children, based on for example income, sex, age, race or ethnicity. As discussed previously, countries worldwide should do more to collected disaggregated data. The (non-)availability of data remains influential. Of the twenty-seven countries that were subjected to CRC state reporting in 2016 thirteen countries realized the lowest possible score on the indicator collection and analysis of disaggregated data (indicating that the CO contains only negative remarks on this aspect).

These countries are Benin, Brunei Darussalam, France, Haiti, Ireland, Nauru, Nepal, New Zealand, Pakistan, Saudi Arabia, Sierra Leone, Slovakia and the United Kingdom. The remaining countries realized an ‘average’ score (indicating a combination of positive and negative remarks in the latest Concluding Observations). Only thirteen countries of the twenty-seven countries that were subjected to CRC state reporting in 2016 received a score on all seven indicators. These countries are Haiti, Iran, Kenya, Latvia, Maldives, Nauru, Oman, Pakistan, Peru, Saudi Arabia, Sierra Leone, Slovakia and South Africa. For the remaining countries at least one indicator was missing.

7) Cooperation between the state and civil society should improve

For effective implementation of the Convention on the Rights of the Child governments need to work together with civil society organisations. Unfortunately, cooperation between the state and civil society is in some countries far from a positive reality. Alarming is the growing concern for the safety of children’s rights defenders, journalists and civil society activists, working to protect the rights of all children in societies.

The KidsRights Index 2017 makes notice of at least 24 countries where children’s rights defenders are harassed, under threat, abused and jailed. Countries should ensure that abuses against children’s rights defenders, journalists and civil society activists are prevented and otherwise independently investigated. The people responsible should be held accountable and punished where due. 35 (out of 163) countries score ‘bad’ on state-civil society cooperation. A lot of data is missing for this indicator in the KidsRights Index, as only for 115 (out of 165) countries information is available on state-civil society cooperation.



KIDSRIGHTS

Index

The KidsRights Index is the only annual global ranking on how countries worldwide are adhering to children's rights.

165 COUNTRIES

Unique: domain Child Rights Environment provides insight into the extent to which a country is equipped to carry out the UN CRC.

Online: the KidsRights Index is accessible for everybody on kidsrightsindex.org

The goal of the KidsRights Index is to stimulate compliance with children's rights worldwide.

The UN Convention on the Rights of the Child is the global framework for children's rights.

1989 UN Convention on the Rights of the Child.

196 STATES

The KidsRights Index uses existing data from two reputable sources: quantitative data published and regularly updated by UNICEF at www.data.unicef.org and the *Concluding Observations* by the UN Committee on the Rights of the Child.

The KidsRights Index: 23 indicators: 16 quantitative and 7 qualitative indicators

1. Life
- Under 5 mortality rate
- Life expectancy at birth
- Maternal mortality ratio

2. Health
- % of under five year olds suffering from underweight
- Immunization of 1 year old children
- % of population using improved sanitation facilities (urban and rural)
- % of population using improved drinking water sources (urban and rural)

3. Education
- Primary school participation
- Secondary school participation
- Primary school enrolment ratios (female as % of male)
- Secondary school enrolment ratios (female as % of male)
- Survival rate to last grade of primary (female as % of male)
- Primary school net attendance ratio (rural)

4. Protection
- Child labour
- Adolescent birth rate
- Birth registration

5. Child Rights Environment
- Non-discrimination
- Best interests of the child
- Enabling legislation
- Best available budget
- Respect for the views of the child/child participation
- Collection and analysis of disaggregate data
- State-civil society cooperation for child rights

The KidsRights Index is an initiative of the KidsRights Foundation, in cooperation with Erasmus University Rotterdam; Erasmus School of Economics and the International Institute of Social Studies.

KIDS RIGHTS

Erasmus School of Economics

International Institute of Social Studies

WHEN THE VOICE IS NOT HEARD

SURVIVAL of JANET WILLICOTT
Abuse and Misappropriation of UK Tax Payers Money
ABUSE OF CITIZEN - ABUSE OF CHILD

I am a mother – I have child, registered as having a rare disability - who also needs an Education

I LIVE IN THE UNITED KINGDOM

THE YEAR IS 2017 - FIGHTING THE UK GOVERNMENT FOR OVER 9 YEARS

UK AND INTERNATIONAL DUE PROCESS
1. 1 x Conservative Committee – Parliament Lobby Bundle to (David Cameron and Nick Clegg for Intervention – both cited incorrect Legislation and Due Process Management) – Complete Failure in administration by LA – **FAILED TO LISTEN TO CHILDS VOICE**.
2. 1 x Magistrates Court Trial - Accused of abusing Bastian's Public Funded Disability Allowances, for Bastian's care allowance whilst being a mature student. The Local Authority failed to check documentation pertaining to Bastian's allowance, judiciary ruled that all documents and declarations were filed, and held on record with the LA. – Not Guilty (LA, failed to thoroughly investigate declarations.) [Threatened with.......5 year sentence and £20 000 fine, Criminal Record] (2014) **NOT GUILTY**
3. 1 x Educational Tribunal via SENDist, appealing Part 4 [Placement] – Appeal Withheld (SENDist ruled in favour of the LA, by using legislation - 'Not best use of Public Resource' – despite the placement 'costed' out as being 'cost neutral' to the public's purse.) (2014) – **FAILED TO LISTEN TO CHILDS VOICE**.
4. 1 x Magistrates Court Trial - Accused of failing to comply with an unlawful (SAO) School Attendance Order, despite the defendant being within the law to lawfully and legally home educate. – Not Guilty (LA, failed to comply with legislation, failed to understand the law, and ruled that the LA had committed a State Crime, withdrew before ruling.) [Threatened with.......3 to 6 months sentence and £10 000 fine, Criminal Record] (2014-2016) **NOT GUILTY**
5. 1 x High Court Application in submission for Judicial Review, based on the SENDist Tribunal Decision. – Application Withheld (High Court and Barristers Chambers ruled that it would not a yield an effective remedy based on the time scale of litigation, and best use of public resources, as the High Court costs would be higher than that of the schooling placement.) (2015) **FAILED TO LISTEN TO CHILDS VOICE**.
6. 1 x Magistrates Court Trial - Accused of failing to comply with an unlawful (SAO) School Attendance Order, despite the LA knowing they were committing a further State Crime. – Local Authority Conceded (LA, failed to comply with legislation, failed to understand the law, and ruled that the LA had committed a State Crime, withdrew before ruling.) [Threatened with 3 to 6 months sentence and £10 000 fine, Criminal Record] (2016) **NOT GUILTY**
7. 1 x European Court of Human Rights submission – seeking resolve for UK Human Rights Educational failings. – Application / Trial Process heard by EC Chambers, it was ruled that before the case could be heard at Grand Chamber Tier, the UK must comply with the Child Rights Charter and an application to High Court must be allowed, it was further recommended that a combined Discrimination, Inclusion, Rare Disease Strategy and Damages application be filed simultaneously. (2016) **UK MUST COMPLY AND HEAR BASTIAN'S VOICE**.
8. 1 x Educational Tribunal via SENDist, appealing Part 4 [Placement] – Appeal Withheld (SENDist ruled in favour of the LA, by using legislation - 'Not best use of Public Resource' – despite the placement costed as being 'cost neutral' to the public's purse.) **FAILED TO LISTEN TO CHILDS VOICE**.

9. 1 x Legal s17 Assessment - Rare Disease - Disability Assessment – Disability Children’s Team/Child in Need Team (Social Services) May 2009, 2010, 2011, 2012, 2013, 2014, 2015, REFUSED on the grounds that it was complex - May 2016 in instructed Judicial Review Proceedings for LA being in breach of legislation and noncompliance and refusal to assess based on Rare Disease Strategy, s17 [UK] and {EHCP} – 8 Years, 11 months and 3 days – LA conceded with a statement: “We did not have Bastian’s Folder”…… Social Services Blamed the SEND Education Department; the SEND Department Blamed the Social Services Department. **ASSESEEMENT GRANTED AND CARE PROVIDED (2017). THE CASE TOOK 8 YEARS, 11 MONTHS AND 3 DAYS TO BE RESOLVED**. **FAILED TO LISTEN TO CHILDS VOICE**.
10. 1 x SEND DEPARTMENT/SOCIAL SERVICES request for JW to consider SEND Negotiations (December 2016) – JW duly compiles and produces entire Negotiating bundle as underwritten by Hertfordshire County Council and School on behalf of Barnet LA. (March 2017) BARNET make a U-turn and refuse to negotiate. **LA HALTED NEGOTATIONS (2017) FAILED TO LISTEN TO CHILDS VOICE**.
11. 1 x LOBBY PROCESS – CONSERVATIVE COMMITTEE Meeting and Intervention process (April 2017) – JW instructed to produce dossier and legal chronology. [Lobby on why have LA and SENDist scrapped all professional reporting for Bastian] – JW Submits formal bundle to Parliament (April) **PENDING**
12. *1 x County Court → High Court Submission (Tort/Negligence for Damages) using legislated regulations pertaining to Disability Discrimination Act, Child Rights Act, Child and Families Act, Disability and Inclusion Act, Equality Act, Rare Disease Strategy, Human Rights Act and Child Rights Charter. (Pending Mid 2017) **PENDING**
13. *1 x Supreme Court Submission depending on outcome of County/High Court Ruling. (Pending - 2018) **PENDING**
14. *1 x ECHR (Grand Chamber) Submission for ruling against the UK – depending on our come of Supreme Court. (Pending - 2019) **PENDING**
15. *1 x United Nations Hearing Submission for recommendations to UK. (Pending - 2019) **PENDING**

The Universal Declaration of Human Rights

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,
Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, Therefore THE GENERAL ASSEMBLY proclaims THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.”

The Europeans Commission’s European Disability Strategy 2010-2020, adopted in 2010, builds on the UNCRPD and takes into account the experience of the Disability Action Plan 2004-2010

Education and Training: Promote inclusive education and lifelong learning for students and pupils with disabilities. Equal access to quality and lifelong learning enables disabled people to participate fully in society and improve their quality of life. The European Commission has launched several educational initiatives for disabled people. These include the European Agency for Development in Special Needs Education as well as a specific study group on disability and lifelong learning.

“*To conquer the struggle, one needs to accept the fight, rather than fight against the pugnacity thereof. Nothing Changes if Nothing Changes*!”
Willicott (2017)

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STATEMENT – BASTIAN WILLICOTT

"I JUST WANT PEOPLE TO SEE ME AS NORMAL MOMMY, BECAUSE I AM NORMAL LIKE ME, AND EVERYBODY IS NORMAL LIKE THEMSELVES, WHY CAN'T SOME PEOPLE UNDERSTAND THIS. ALL CHILDREN JUST WANT TO BE HAPPY, LIKE ME".

BJA Willicott (2016)

"I have a voice Mommy; I am also normal."

BJA Willicott (2017)

QUESTION – JANET WILLICOTT

The United Kingdom has an unwritten constitution; the UK is also a Sovereign State – with the Head of State being a Monarch, namely a Queen 'Queen Elizabeth II' – The Queen, as Head of State, oversees her Kingdom by virtue of religious order - therefore the unwritten constitution is guided by 'The Holy Trinity' – so when in a Court of Law – one is always reminded that one is under oath to the said 'Holy Trinity'; yet,

Who or What is the 'Holy Trinity'?

If I am under oath to the 'Holy Trinity' why then, must I, as a parent, submit evidence for my instinctive knowing?

One cannot offer evidence on instinctive knowing – for it is only felt, however at the same time I must, as a citizen abide with a 'Holy Trinity' for which there has never been any evidence!

[One only needs to refer for ease of reference to the USA – The USA has a written Constitution – which is underpinned by the following:

'In God We Trust' – However, who is 'God' and where is the god evidence?]

CONTRADICTION IN TERMS

How an Oppugning Schooling Placement and Environment can Adversely Affect a Child's Mental Health & Emotional Development across the SEND Spectrum.

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