

Contact



The PAPA Newsletter

Issue No. 31 MARCH 2004

SPECIAL EDITION



Important facts about Autism and Asperger's Syndrome for GPs

What type of disabilities are Autism and Asperger's Syndrome?

- developmental – affecting social and communication skills
- life-long
- part of a range within what is termed 'the autistic spectrum'
- wide ranging – some people have accompanying learning disabilities while others have average or above average intelligence.
- affecting boys more often than girls – classic autism sex ratio is four males to one female; for Asperger's Syndrome it is nine males to one female



WHO WE ARE AND WHERE

WE'VE BEEN

For those of you who have not lived through the birth and early years development of PAPA, this I hope will give you an understanding of why we are the charity we are to day.

A Reflection on how far we've come

by Liz Aiken

(PAPA Chair)

In the late 1980's a social worker, Maureen Gordon, in Down Lisburn Trust was involved with a growing number of families and children where autism was suspected. Through the work of Maureen and other professionals involved, a group of interested parents and professionals was formed.

In 1991 a Conference was held at Stranmillis College jointly facilitated by Barnardos raising the awareness of autism. A group was now meeting each month in Lisburn but was increasingly being attended by folk from all over the province. The benefit for parents was two fold, meeting professionals who have an understanding of autism and meeting other parents who you neither had to explain your child to, nor apologise for their different behaviours. Professionals were also gaining from the association. Hence the needs of both groups were clearly identified. This was not just a parent group facilitated by professionals, nor a professional forum, therefore PAPA was formed: Parents and Professionals and Autism! In 1990 charitable status was granted.

It became increasingly evident that the charity needed to grow and develop to meet the need of a province wide membership. Difficult soul searching took place and a one-room attic office was opened and an advertisement was put in the press for a Development Officer. Arlene Cassidy was duly appointed and took up a part time post in 1992.

At this stage we had precious little money. It really did need the books carefully balanced to

meet salaries and bills. Arlene's first job was to try to gain funding for her post while developing a network of PAPA Branches.

1992 saw the introduction of TEACCH into N. Ireland after a parent read about the approach and brought it to the attention of professionals involved with the Charity. They further investigated what it was about and after attending training in England realized we needed this knowledge in N. Ireland. A conference was held which lead to the TEACCH pilot programme being launched after two-year research by the University of Ulster. In the 1990's further research was commissioned with diagnosis and early intervention and this has lead to a strong partnership with the NAS in the delivery of diagnostic training. A lot of other training in different interventions and strategies has taken place and been integrated into service provision. So much has been achieved but so may more improvements are needed in the development of services and enhancement of staff skills.

During the intervening years the staff team grew to the present quota of Director, 2 full time and 1 part time Development Officers, 2 Admin staff, 1 part time Office Assistant, and one seconded Early Intervention Therapist for Western Board. Over the years the Branch network has also developed to our current position of supporting 13 Branches and looking back we have cut through a wilderness of ignorance. Many may feel we still have a long way to go but now there is an army of Parents and Professionals marching forward together.

Together united for Autism we will be strong, PAPA endeavours to be a lobbying organisation for the whole spectrum irrespective of age or ability. This is where we came in and this I trust is who we will continue to be.

OPENING OF NEW PREMISES

The 27th of September will be noted as a momentous day in the life of PAPA. PAPA are beginning to leave the title "small local charity" behind us, confirmation of this was the attendance of Lorna Wing at our AGM, and opening of new office premises at Donard House Knockbracken. Dr Wing is the autism equivalent of a superstar! And she came out of retirement and made the trip from London to do PAPA the honour of opening our new premises and setting us on the road of becoming a nationally recognised campaigner for autism rights. Lorna Wing is responsible for discovering and naming Asperger's Syndrome as a recognised condition, and is the creator of the concept of an Autistic Spectrum, and the Triad of Impairments. In

other words she dragged autism out of the dark ages, out of the age where Kanner's autism seemed to be the only diagnostic option, and into an age where we recognise that Kanner's is only one end of a complex spectrum of Social, Imagination and Communication disorders. The contribution and significance of Lorna Wing on the world of autism cannot be underestimated.

I felt like a teenager meeting a popstar! As did the entire PAPA staff and local professionals who gathered to meet Lorna Wing, and Judith Gould, cornerstone figures in the history of Autism. Lorna is not only a professional, but also a parent, of a daughter with autism, and she congratulated PAPA on our enduring ethos of marrying

parental and professional interests in autism – this is the way forward, and who better to confirm this.

The new resource centre boasts: A fully equipped conference venue, which can house up to 100 delegates, two new training rooms, a family room, study rooms for students and professionals, and a new larger library. The move has also cemented the existing relationship between PAPA and Autism Initiatives. Autism Initiatives is becoming the main service provider for adults in N Ireland, and is an existing linchpin in the network of service provision in Liverpool and the Isle of Man.

PAPA and Autism Initiatives now share Donard Centre.



Back Row - from left - Janette Hand, Gillian Henderson, Carole Murray, Arlene Cassidy, Dr. Judith Gould, Fiona McCaffrey, Jackie Addis. Front Row - Dr Lorna Wing, Liz Aiken, David Heatley

There is nothing new under the sun

Looking back into history the educated eye can observe numerous figures across cultures that could reasonably assumed to have had an Autistic Spectrum Disorder.

A brief history of Autism by Lorna Wing

Lorna then gave her own perspective on the ground-breaking Camberwell Study, which for the first time demonstrated that Kanner's autism was a subtype of a larger spectrum.

These historical figures are cross-cultural and date back as far as the 11 Century.

- Brother Juniper an 11 Century Monk who endeavoured to carry out the instructions of the Bible word for word, he gave away the entire Monastery gold and silver to a beggar, as well as his own clothes!
- The Wild Boy of Aveyron a boy taken in from the woods of France and examined by the main medical minds of the day. He was observed to be non-verbal, have sensory acuities, a desire for routine, and a lack of desire to engage with people around him.
- Russian "Holy Fools"
- The 18 Century Scottish Writer Hugh Blair

Later in the 19th Century Henry Maudsley grouped together a number of children whom he claimed to have "insane" brain damage. Later the term "Instinctive Insanity" was used to describe children who lacked social instincts. Another terminology used was "Childhood Psychosis".

The terminologies used to describe unusual behaviour in children was varied until Kanner identified what he called "Early Infantile Autism" in 1943.

Only months after Kanner's report was published, Hans Asperger, an Austrian Paediatrician reported on a condition he called "Autistic Pathology". He identified a pattern of behaviours and abilities which greatly resembled the population identified by Kanner. "Autism" was a term coined by Bluer in 1911 to describe withdrawal in Schizophrenia.

Kanner did at this stage underline that autism is a separate condition from Schizophrenia.

Possible explanations for autism were heavily influenced by the prevailing thoughts of the day. In a Post-Freudian world parents and child rearing were implicated heavily in autism up until the biological model was revisited in the mid 1960s.

The Camberwell Study highlighted the fact that a lot of children who presented with autism actually had no learning disability, or language delay. Or in Lorna's own words children with "bits of Kanner."

They also identified a group of children who demonstrated behaviour similar to that described by Asperger.

From this the idea that autism was actually a spectrum centered around three core impairments germinated.

These three core impairments are now familiar as the Triad of Impairments –

- Social
- Communication
- Imagination

These can have a wide range of manifestation with no clear dividing line. Some aspects of this Triad are necessary for great scientific or artistic achievement. Lorna then quoted Temple Grandin.

"Without the gene that causes autism we'd all still be sitting in caves talking about feelings and emotions!"



Judith and Lorna

GP BOOKLET

PAPA also launched a new information booklet –
“Important Facts about Autism and Asperger’s Syndrome for GP’s”

The booklet is the result of consultation between PAPA Staff and the PAPA Board, and sets out the common signs and symptoms of Autistic Spectrum Disorder in a clear and concise fashion. The booklet contains the Check List for Autism in Toddlers (CHAT) a screening tool for GP’s and Health Visitors, and Gillberg ‘s Diagnostic Criterion for Asperger’s Syndrome. PAPA hopes to circulate the booklet to GP’s Surgeries throughout N Ireland. Copies are available from PAPA Central at a nominal cost of 25 pence.



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BOOK REVIEW

The Curious Incident of the Dog in the Night Time

They say you should never judge a book by its cover: well to that I would like to add or by its title!

Believe me, *The Curious Incident of the Dog in the Night-Time* (TCITDNT) by Mark Haddon, a work of fiction, deserves its place in a collection of books on raising public awareness of Autistic Spectrum Disorder (ASD).

Mark Haddon is a successful children's author and because in this his latest work he has continued in his simplistic style, it has been classified as a book for children. But by doing this and thus excluding adults, I believe a great opportunity has been wasted.

There are shades of *Adrian Mole* in Christopher's (Main character who has Asperger's Syndrome) style; the reader must think around the written word to understand what is happening in Christopher's world. It is a very effective and timely reminder that having autism is a constant state. Like most of us I can only comment on the accuracy of Christopher's character as one looking in with my own experience as a mother of a now adult child. I felt that it was a heartfelt, thoughtful and consistent portrayal. Without giving too much of the plot away, the occasional attempts of Christopher to explain his arbitrary behaviour are extremely interesting and valuable. Again not to say too much, Christopher's parents are also excellently written.

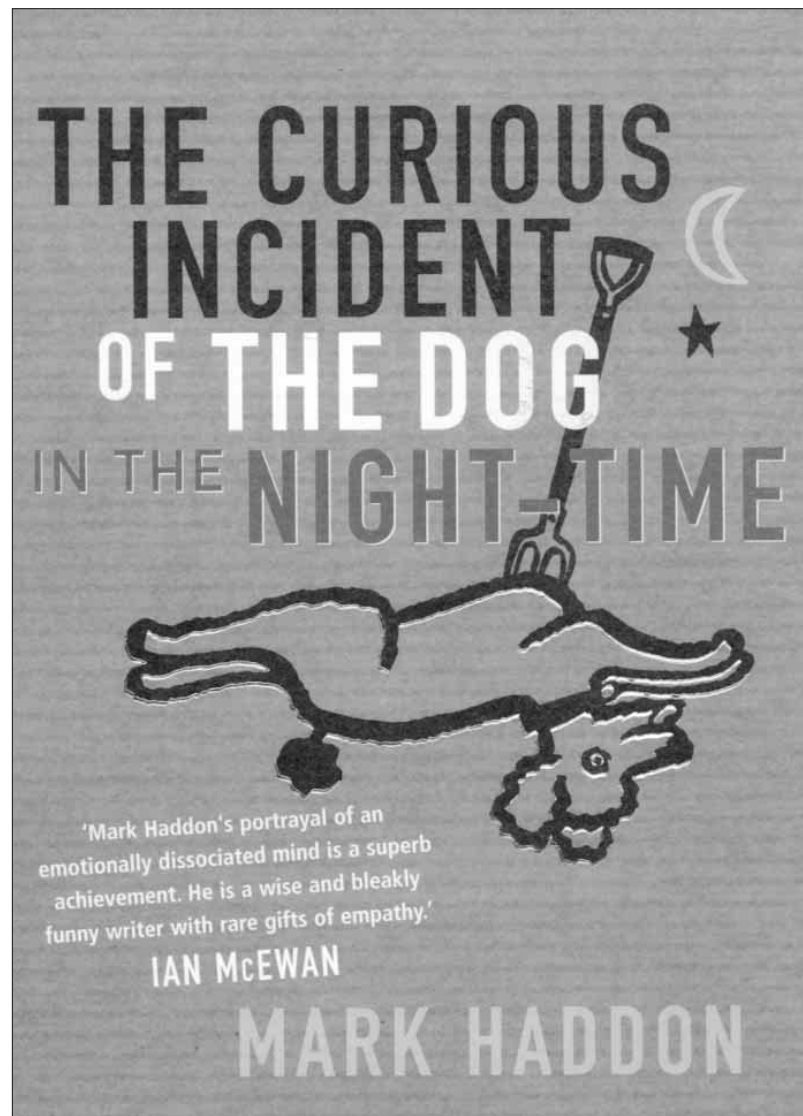
The family dynamics having revolved around Christopher's development are authentic. Having a child with special needs particularly ones as emotive as Christopher's is highly stressful and will test all marriages.

TCITDNT is a novel meant to entertain and it could potentially do so much to raise public awareness if ASD.

A family friend, who is rather too fond of *Prime Numbers*, discovered this book said that he understood my son's behaviour much better from having read this book. What stronger accolade can you have?

The Curious Incident of the Dog in the Night Time won the Whitbread Book of the Year. One judge rhapsodised that the book had "*used disability to throw a light upon the world*". The book has also scooped the South Bank Show Award for Best Book won the Guardian children's fiction prize, and the Book Trust fiction prize. It missed out on the Booker Prize, but probably did even better in publicity terms when John Carey, chairman of the judges, publicly lamented the failure of his fellow judges to appreciate a "masterly and amazing" book.

By EILISH STOCKS – Parent



SPECIAL REPORT ON AUTISM EUROPE CONFERENCE - LISBON

Around last August when I (Fiona) volunteered to be PAPA's "roving reporter" at the Autism Europe conference in Lisbon, it all seemed like a good idea. Months later, sweating in Lisbon airport it didn't feel like such a good idea.

Losing my luggage was worrying, the fact that the only language I have apart from English is schoolgirl French, was slightly more worrying. However perhaps the most alarming development that afternoon was the fact that I had somehow acquired a heavy Spanish accent, which persisted throughout the weekend!

Arriving at the conference venue, I remembered why this was a good idea. The line up was simply mouth-watering for anyone interested in autism. To mention a few names – Rita Jordan, Simon Baron-Cohen, Uta Frith, Eric Fombone, Paul Shattock, Catherine

Lord. I couldn't wait.

The Theme of this year's conference is "Dreams Guide Life" and this was very much evident at the opening ceremony of the conference.

The colours of the spectrum were splashed onto an international canvas. Reminding all there, that autism is a worldwide issue, which extends far beyond our own physical and political horizons. It was slightly humbling to converse with colleagues from Europe and beyond, it also offered me the gift of perspective, something which often can only be had when you are "outside the box."

Then it was down to business.

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presents

The Colours of the Spectrum

with Guest Speakers

Temple Grandin

University of Colorado USA

and Gary Mesibov

Division T.E.A.C.C.H., University of N. Carolina USA

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E-mail: info@autismni.org

AUTISM EUROPE CONFERENCE - LISBON

JUAN MARTOS :

“Diagnostic of young children with autism: A Review”

The Speaker had carried out research into the individual and family characteristics of his sample – 72 children with a diagnosis of autism. These were:

- Family History
- Age of parents at pregnancy moment
- Sex Distribution of ASD in sample
- Position of child in family
- Profession of parents
- Prenatal complications in mother
- Selectivity of food
- Passivity in the first year
- Mean age of child when parents first became suspicious
- Most frequent symptoms
- Medical assessment
- Motor Development

Family History of Pathology	36% No Pathology	19% Language Disorder	13% Learning Disability	11% Epilepsy	5% “Other”
Age of parents at pregnancy moment	Mother 33.44 yrs	Father 35.44 yrs			
Sex Distribution of ASD in sample (N=72)	88% Male	12% Female	Overall Ratio 1-7.4		
Position of child in family	49% Second	27% Only	17% First	7% Third	
Profession of parents					
Father	Engineer 15%	Business 15%	Teacher 9%	Lawyer 7%	Admin 5%
Mother	Home Maker 20%	Admin 15%	Teacher 7%	Lawyer 7%	Doctor 5%
Prenatal complications in mother	26% C Section	14% Diabetes	7% Induced Labour	7% Turn Umbilical Cord	
Selectivity of food	60% No	40% Yes			
Passivity in the first year	67% No	37% Yes			
Mean age of child when parents first became suspicious	19.66 Months (SD 4.5)				
Most frequent symptoms	43% No Language	43% Paradoxical Deafness	31% Lack of Eye Gaze	24% Language Loss	26% Aloofness
Medical assessment	83% No Brain Findings	17% Brain Abnormalities			
Motor Development	74% Normal	34% Slight delay	2% Delay		

AUTISM EUROPE CONFERENCE - LISBON

RUTH RAYMAEKER: representing a research group from the University of Ghent.

This group has been researching a screening instrument for identification of autism in preschoolers

Early identification is crucial in autism; the researchers commented that although parents may start to notice something is wrong with their child, between the ages of 16-20 months, the average age of diagnosis in Belgium is aged 4-5. This leaves a huge gap. Obviously it is difficult to diagnose autism at a very early age, and the initial symptoms can be ambiguous. However there is also a need for a stable, and user-friendly screening instrument to enable earlier diagnosis, and increase awareness.

The Group used the "Social Communication Questionnaire" (Beruiant 1999)

They distributed this to a non-clinical sample throughout the Flemish School System this comprised a sample of 5402 children. The questionnaire is

user friendly, and was used by parents, and professionals alike.

Out of this sample 2.7% children scored above the cut off – indicating that there may be problems with their social communication.

A breakdown of the result

Sample Size	ASD	Male	Female	SEN
N=5402	0.6%	73%	26%	43%
	34	25	9	14

The researchers calculated that the Social Communication Questionnaire had a positive predictive value of 73% for all Developmental Disorders. Thus they felt this was a functional instrument.

HIDEO ITTOH:

Early Symptoms and Diagnosis of Autism in Infants

This study was based in Japan. In Japan children have 3 health checkups – 3-4 Months, 18 Months, 3 Years

The study used diagnostic criterion for a number of conditions from the 18mth screening.

These disorders were

- Pervasive Developmental Disorder (PDD)
- Learning Disability (LD)
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autistic Spectrum Disorder (ASD)

The results indicated that the following diagnostic criterion were found to be most common in the above conditions

- Lack of facial expression
- Lack of imitation
- Lack of emotional reciprocity

- Lack of receptive language
- Bizarre play
- Prefers to play with switches and machines

From this criterion the researchers were able to identify the following criterion as being the main differing criterion between the diagnosis of PDD and ASD.

- Lack of facial expression
- Lack of eye contact
- Does not play with regular toys
- Hyperactivity

The researchers acknowledged that autism cannot be discriminated from other developmental disorders at 18 months, however the above diagnostic criterion do seem to be more related with autism at the 18mth stage.

AUTISM EUROPE CONFERENCE - LISBON

HELMUT REMSCHINDT: “Differential Diagnosis of ASD”

Helmut addressed the need for differential diagnosis and referred to common conditions associated with ASD. Initially he addressed the question – why do we sometimes need a differential diagnosis?

- There are different kinds of disorders within Pervasive Developmental Disorders (PDD).
- Different disorders will have different manifestations, and require different treatments and interventions.
- Defining sub-types of disorders enhances our understanding of the disorder, for example, Diabetes.

Within the ICD-10 and the DSM IV there are similar sub-groups of PDD's these are

DSM IV

- Childhood Autism
- Atypical Autism
- Heller's Syndrome
(Childhood Disintegrative Disorder)
- Rett's Syndrome

ICD-10

- Autistic Disorder
- Rett's Syndrome
- Childhood Disintegrative Disorder

The defining features of ASD, which differentiates it from other PDDs – Onset in early childhood, steady course with no remissions or relapses.

Helmut outlined the “Six Steps to Diagnosis”

1. Suspicion
2. Screening
3. Comprehensive assessment
4. Differential Diagnosis
5. Multi Axial Diagnosis
6. Treatment

Children with a diagnosis of ASD will have gone through an intensive diagnostic procedure. Helmut then showed a video showing the differences in play and joint referencing between a child with an ASD and a child with PDD. The differences were very apparent between the children, particularly in the areas of – affect, joint attention, shared enjoyment, pointing, and requesting.

It is important for diagnosticians to be knowledgeable of the differences in presentation in PDDs and between PDDs and other disorders.

ERIC FOMBONNE: “Epidemiology and Genetics”

Has there been, or is the ongoing an “autism epidemic?”

There have been 40 surveys of Epidemiology since 1966, in 14 different countries.

Most of the studies have been cross-sectional, snapshot studies. These studies have had vastly differing methodologies and used different screening and diagnostic tools.

Fombonne believes that these studies cannot be compared because the methodologies are so different, and its not a case of comparing “like with like.”

Thus from these its difficult to say categorically that there is an “autism epidemic” because the studies are so different, using different measures and concepts of autism.

Probably one of the most widely quoted studies, which indicates a rise in diagnosis, and incidence of autism is the California Study of 2001. What isn't so well known is that education law in California had changed in 1990/91, meaning that diagnosis of autism had by law to be reported to the Dept of Education. Naturally this is going to have an effect on the statistics. Fombonne stated that viewed in this perspective the word “epidemic” could hardly be used.

Regarding the MMR Fombonne believes there is no connection between the MMR and autism. In my notes I wrote in brackets – “ I can see Paul Shattock shaking his head” Paul was to take to the stage directly after Fombonne, and it looked like the afternoon was heating up nicely! Fombonne quoted a Danish Study, which indicated that there is no relationship between the MMR Vaccination and the development of Autistic Spectrum Disorders (Madsen 2002) Fombonne went on to discuss the risk of Mercury in vaccinations, saying that there is no Mercury in the MMR, and the use of Mercury has been discontinued in Denmark, and the reports of autism still continue to rise.

Fombonne placed much more weight on a Genetic argument A study by Bailey (1995) indicated that there was a 60% chance of monozygotic twins both developing autism, and in some families if a member did not develop autism a family member would be likely to develop an autistic like disorder, or as the speaker put it a “broad phenotype”

The establishment of clear Genetic links in autism is a real step forward, this is the gateway to understanding the nature of autism, the correlation of a broad phenotype, the identification of at risk, and protective factors.

AUTISM EUROPE CONFERENCE - LISBON

PAUL SHATTOCK:

“Environmental Factors in the Causation of Autism”

As would be expected Paul disagreed with much of what Fombonne had to say, the refreshing element to this, is that there were also areas where he agreed with Fombonne. Taking the areas of divergence first, Shattock argued that while Fombonne’s points were valid, there was still no getting away from the fact that autism is on the rise. For this he first cites environmental reasons, and the fact that other conditions are on the rise, conditions like Asthma, Cancers, Meningitis, and peanut allergies. There are more pesticides being used, our diet has changed leading to different bacteria in our guts, the presence of more Heavy

Metals in the environment, plasticisers, toxic fumes, food additives and drug residues – in short everything has changed!

Regarding the MMR, he admits that epidemiological evidence does not support a link, however 10% of parents in the UK claim that this was a factor in their child’s autism. In the USA 50% of parents claim that the MMR caused their child’s autism. He argues that even if the MMR is responsible for a tiny number of cases of autism, is this not justification in itself of offering an alternative.

RUTGER VAN DER GAAG:

“Co-morbidity in autistic spectrum disorders: classification artefact and a clinical reality. A pragmatic approach”

The most common co-morbidities are:

Anxiety 65%

Hyperactivity 50%

Aggression 43%

Obsessions 40%

Depression 32%

Hallucinations 18%

Tics 2%

(Klin & Volkmar)

If we respond to the above co-morbidities as a classification artefact we need to be absolutely sure that this is what they are. Otherwise we will be ignoring the whole phenotype. For example we need to be able to differentiate between Hyperactivity and ADHD, between Obsessions and Preoccupations and arousal dysregulations from generalised anxiety. There is a need for thorough assessment or there is a real risk of associated conditions being ignored as the existing pathology becomes increasingly classified.

Van der Gaag suggests we use an ABC model to completely look at co-morbidities. This is Antecedents, Behaviour, and Consequences.

Antecedents – What has changed in the child/adult’s life? What is coming up in their life? Which events could be related to the present situation?

Behaviour – Was it anger or anxiety? When did we see it before? Can we discern from the antecedents how it happened?

Consequences – What are the negative affects? What are the advantages? Can we discern there?

This examination has distinct consequences for any treatment plan.

Our understanding of co-morbidity will change when we have more comprehensive multi-axial diagnosis of autistic spectrum disorders.

NEXT Edition of Contact

- RETURN OF KIDS PAGE
- REVIEW OF STRATEGIC PLANNING WEEKEND
- REVIEW OF TRIP TO NEW YORK
- LAUNCH OF NEW INFO BOOKLET

AUTISM EUROPE CONFERENCE - LISBON

SIMON BARON-COHEN: *“Is autism an extreme of the male brain”*

Baron-Cohen produced some interesting evidence to support this rather controversial theory – I was lucky in that I had just finished reading the book – so I felt already well informed on this.

Basically Baron-Cohen claims that foetal testosterone levels will have a direct effect on brain development, and subsequently behaviour.

He claims there are two broad brain types – Systemisers (S), and Empathisers (E). A systemising brain is an analytical brain which processes facts, enjoys the factual and the concrete, the brain of the scientist. The empathising brain is more tuned into the emotional side of life, and is not so factually based, but is more of a feeling based. Obviously then he claims that men are more likely to have type S brains, and women are more likely to have type E brain. This is extremely tentative and

Baron-Cohen goes to great lengths to ensure that no possible generalisations could be made, and that all men do not have type S any more than all women have type E. However there does appear to be a relationship. Obviously then we can say categorically that people with autistic spectrum disorder will be more likely to have an extreme type S brain. Most people with Autistic Spectrum Disorder will have more factually based interests, and be less likely to be interested in the more emotional side of life. He backs this up by the fact that men are more likely to be engineers, computer programmers, architects, in fact any of the professions requiring concrete factual based analysis are likely to be male dominated. Equally professions such as counselling or nursing, are seen as female dominated, professions relating to caring, and being in tune with the feelings of others.

Men do score more highly than women on tests requiring analytical skills in University aptitude tests, and taking this further people with an Autistic Spectrum Disorder are more likely to score more highly than neurotypical males on such tests. In a study of maths students in Cambridge University 378 people on this male dominated course already have a diagnosis of Autistic Spectrum Disorder this is almost 2%. In a social Science Course studied only 0.2% of the students had a diagnosis of Autistic Spectrum Disorder. There is also a higher rate of Autistic Spectrum Disorder amongst the siblings of the maths students tested.

This is not a “theory” as such, but the evidence is mounting that there could be some sort of relationship, and that indeed autism could be some extreme variant of the male brain.

CATHERINE LORD: *“Evidence Based Treatment of A.S.D.”*

Catherine Lord and her colleagues at the University of Michigan carried out an extensive review of the research into autism interventions in the USA. This is a massive undertaking to review all this literature. The researchers used three broad approaches to this review.

- Review all published literature
- Select up to date information
- Follow back theories and other related research.

The researchers applied extremely rigorous validity criterion, very few studies met this criterion.

The characteristics of effective interventions were grouped; the interventions themselves were from differing philosophies however there were core similarities with all the effective interventions. These were:

- Early intervention
- Intense instruction 25 hrs per week as a minimum

- Individual one to one attention on a daily basis
- Systematically planned, developmentally appropriate activities aimed toward identified objects
- All had a family component
- Interventions that occur in a naturalised context are more likely to be generalised and maintained.

Other features that were considered in effective interventions were:

- The priorities of the programme – was it aimed at
- The time spent on different domains
- The use of one set of procedures as opposed to a combined approach
- When children are considered for inclusion
- How the role of peers is supported
- Use of distraction free or natural environments
- Staff credentials and qualifications

More information on the study can be found on www.umich.edu/~umacc

AUTISM EUROPE CONFERENCE - LISBON

UTA FRITH: *“How do cognitive theories help us to understand autism?”*

One of the speakers I had been most looking forward to was Uta Frith.

Autism is mostly defined at a biological level, cognitive explanations are the bridge between the biological and the behavioural, however we must not ignore the very real and very important effects of the environment on this. So we can see any sort of behaviour as a mix of biological, cognitive and environmental factors.

Taking cognition as the subject of her talk Uta Frith discussed the main cognitive theories in autism.

■ **Theory of Mind.** People with autism have “mind blindness” an inability to mind read, and an inability to appreciate the fact that other people may have differing thoughts, feelings, and beliefs to them. There is a neural basis for this; part of the limbic system in the social brain has been identified as having reduced activity that in

neurotypicals when faced with a test of Theory of Mind.

■ **Executive Functioning.** This is a range of higher order control processes, our ability to plan ahead, monitor our behaviour during and after goal related behaviour, an ability to hold, and manipulate information in mind, ability to do several things at once, and an ability to inhibit no longer needed behaviour. This also includes, ability to react flexibly in the face of change, to dis-engage attention when it has been grabbed.

■ **Weak Central Coherence.** Basically this refers to a style of information processing where the tendency is to process small details at the expense of any global meaning. This leads to enhanced perceptual discrimination, excellent rote memory, excellent visuo-spatial skills, and ultimately paves the way for savant skills. People with autism and their relatives are

more likely to have this style of information processing, and this in turn accommodates and generates the development of very specialised interests.

These cognitive theories and explanations of certain behaviour within the autistic spectrum have obvious advantages and disadvantages – certainly they can go some way to explaining savant skills, however there are also specific impairments associated with these cognitive styles and people in education and people working with individuals on the autistic spectrum need to be aware of these – teaching methods need to be different to accommodate the different cognitive styles. This would include, explicit teaching, explicit communication skills, concrete explanations, talking through individual experiences, and above all patience, improvement will happen only over time!

RITA JORDAN:

“Practical Implications of Current Psychological theories of Autism”

Rita started off reminding us that autism is essentially a transactional disorder, someone cannot have autism on his/her own! This is a useful theory to keep in mind, it reminded me of a conference I attended some time ago with Wendy Lawson as the speaker. Towards the end of the conference we had questions and answers, and when one individual asked Wendy “what do you think causes autism?” she replied pointing at the audience “you guys!”

Behaviour is our only hook in autism, its all we have really, but we must not get too fixated on the behavioural elements of autism, as autism is much deeper than any behaviour, the behaviour is not autism, the behaviour is a clue to how the person with autism may be feeling, but it is not autism. Just as we need a theory to help us understand people with autism they in turn need a theory to understand us – we just need to be careful we don’t throw the baby out with the bath water when we are building a theory of autism. As previous speakers have warned it is important that we don’t lose behaviours and problems and co-morbidities as we attempt to classify and understand autism. Or as Rita put it, we need to ensure that our “pastry cutter” is not too rigid, when we are cutting out our theory of autism. There are three seminal theories – these are.

1. **Mindblindness / Theory of Mind – Baron-Cohen** – useful applications of this is the knowledge

that certain behaviours need to be taught.

2. **Weak Central Coherence – Happe** this has importance in the way we understand the individuals ability to remember, and memorise and retain information, and in their understanding and perception of the world.

3. **Executive Functioning – Russell** helps us understand the nature of the impulsivity, stopping actions, monitoring own action, immature attention strategies.

Newer theories coming along which may be worth watching out for;

■ **Intersubjectivity – Hobson**

■ **Dichotomy-Boucher**

These all have useful practical applications, especially for those in education, as they illuminate clearly the deficits at a cognitive level.

By the time I had listened, processed, and written up all this information, I was wishing I had went for a less exhausting job, such as shifting blocks of cement, or digging deep ditches! Lisbon was an extremely worthwhile experience, and I do feel so much better informed having been there. I have to add that I am only reporting the views I heard at the conference; none of the above is reflective or indicative of my own beliefs, or the views of PAPA.

LOCAL HAIRDRESSERS FUND-RAISE FOR AUTISM

Andrew Mulvenna

PAPA benefited from two fundraising events organised and hosted by local hairdressers.

The first of these was in November 2003 when Andrew Mulvenna N Ireland Hairdresser of the Year held a "hair meets design and architecture" evening in the Ormeau Gallery.

This was a remarkably special evening jam packed with glamour and creativity. However there was also time in between the glamour and fashion and champagne cocktails to have a good old-fashioned raffle! The proceeds of the evening and the raffle are given to PAPA. PAPA wishes Andrew and all his Team the very best of luck in their new role as one of only ten L'Oreal flagships throughout the UK.



Andrew Mulvenna (right) with world famous hairdresser Trevor Sorbie.



Staff of Peter Marks, Forestside, who took part in the Autism Day

Peter Marks

On Sunday 1st February the hairdressers in eight local Peter Marks volunteered their time and expertise for autism. Initially the brainchild of members of PAPA Lisburn the idea soon caught on and resulted in Peter Marks in Lisburn, Portadown, Arthur Street, Abbey Street, Abbey Centre, Forestside, Ballymena, Antrim, and Newry offering their time and talents on a Sunday to raise money for PAPA.

Many thanks to all who took part.



Peter Marks, Lisburn, who initiated the Fund Raising Day with parent Clare Hughes

LOCAL PROFESSIONALS VISIT THE BIG APPLE

“PAPA – The N.I. Autism Charity, an organisation run by parents and professionals committed to Autism is looking to America to see how it could transform the lives of people with Autism in Northern Ireland”.

A multi professional group of fourteen from Education, Health and Social Services and the Voluntary sector will visit New York to see first hand a Special Education Programme run at B.O.C.E.S, Goshen. The STRIVE programme (Structured Teaching Reinforced in a Visual Environment) focuses on the use of visual teaching as a way of enhancing all areas of learning. It helps students to see language by providing visual symbols to teach concepts, vocabulary and skills.

Arlene Cassidy Director of PAPA explained:

“We were keen to visit New York to see first hand how the Special Education Programme operates. It is based on using visual symbols (Icons) to help students in understanding the world and in giving them the self confidence to know “I can” The strategies they use have been associated with student growth in receptive and expressive language skills, greater confidence to try new tasks, lessened anxiety, increased social skills and improved academic and cognitive skills.”

She went on to say:

“Autism affects people of all ages and all levels of ability so there are implications for Health, Education and Social Services. The trip is all about the continued enhancement of professional skills, increasing the motivation of staff and perhaps more importantly informing service developers who are ultimately responsible for shaping the future services provided for Autism. We are indebted to B.O.C.E.S who have waived their normal programme fee - which would have run into thousands - for the team because of their special relationship with PAPA”
It is estimated that around 3,000 people in N.

Ireland have Autism, a disability that disrupts the development of social and communication skills.

Approximately 50 percent of individuals with Autism have accompanying learning difficulties but whatever their level of ability they share a common difficulty in making sense of the world in the way others do. Many will not be able to relate to their parents or siblings.

It affects four times more boys than girls. The cause is not known nor is there a cure for it but the general belief now is early diagnosis is crucial because it channels the child to the specialist services they need. This visit will ensure that those specialist services are cutting edge.



Aaron Fitzpatrick from Lisburn, one of hundreds of children throughout Northern Ireland who will benefit from U.S.A. visit.

branches

SOUTH BELFAST

Last Monday Each Month
PAPA Head Office 8 pm - 10 pm
1st Saturday Every Other Month
Belvoir Activity Centre 4 pm - 6 pm

WEST BELFAST

Contact PAPA Central

DERRY

3rd Tuesday Each Month
Foyle Hospice, Culmore Road,
Derry 7.30 pm

DUNGANNON

1st Wednesday Each Month
Sperrinview Special School
Dungannon 8.00 pm

NEWRY & MOURNE

2nd Tuesday Each Month
Balmoral Hotel, Warrenpoint 8 pm
1st Saturday Each Month
Orana House, Warrenpoint Road,
Newry 2 pm - 5 pm Play Club

EAST ANTRIM

1st Wednesday Each Month
Ballyclare Community Centre
7.45 pm - 10.00 pm

DONEGAL

2nd Monday Each Month 8.00 pm
Contact Fiona for details

FERMANAGH

3rd Tuesday Each Month 8.00 pm
Killadeas Day Centre
Lackaboy Industrial Estate

NORTH DOWN & ARDS

2nd Tuesday Each Month
10.00 am - Midday
Torbank School, Dundonald
Please contact Jackie

OMAGH 2nd Wednesday 8.00 pm

Each Month - Gortmore House, Omagh

MID ULSTER Last Thursday Each
Month, 8 pm - Maghera Day Centre

CRAIGAVON/BANBRIDGE

2nd Wednesday Each Month
7.30 - 9.30 pm. Clanbrassil
Room, Upper Bann Institute,
Lurgan

DOWN

2nd Last Tuesday
Each Month 8.30 pm
Murlough Tavern, Dundrum

LISBURN

2nd Monday Each Month
Warren Park
7.30 - 9.30 pm
1st Saturday Each Month
2 - 4 pm Lisburn Leisureplex

NORTH COAST

3rd Monday Each Month
Ballysally Community Centre
Coleraine
8.00 pm - 10.00 pm

GWEEDORE

Quarterly - An Chuairt
Contact Fiona for details

staff

Arlene Cassidy, Director: based at Central Office, Monday - Friday: 9.00 - 5.00

Jackie Addis, Development Officer: based at Central Office, Monday - Friday: 9.00 - 5.00

Janette Hand, Administration Officer: based at Central Office, Monday - Friday: 9.00 - 5.00

Fiona McCaffrey, Development Officer: based at Central Office, Monday - Friday: 9.00 - 5.00

Sue Macleod, Development Officer Early Intervention: based at Central Office, Monday - Friday 9.00 - 5.00

Gillian Henderson, Project Administration Officer: based at Central Office, Monday - Friday 9.00 - 5.00

Kathryn Gillespie, Office Assistant: based at Central Office

Florence Trotter, Early Intervention Therapist: based at Central Office

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more information

If there is any information in this newsletter which you require more details on, please contact any of our offices.

disclaimer

The information contained in this publication is presented in the spirit of keeping you informed and aware of developments in the field of Autistic Spectrum Disorders.

Views expressed in "Contact" are those of the authors themselves and not necessarily those of the Editorial Team.