

Durham paper **An Autism Odyssey**

An Autism Odyssey Text **Page 54**

Having a child with autism is a devastating experience. When, rightly or wrongly, parents suspect that it could have been avoided (by not using the combined MMR vaccine for example) the effects are compounded. To be blamed for their problems, to have your children removed from your home with only very occasional visits permitted is unacceptable. To jail parents who are attempting to protect their children is sickening.

We suggest the existence of a syndrome in which officials make false accusations about the fabrication or induction of disorders in children by carers. This syndrome, Munchausen Syndrome by Proxy by Proxy will continue to spread throughout the world unless appropriate interventions are introduced as a matter of urgency.

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Adding Insult to Injury

Munchausen Syndrome by Proxy in Acquired Autism Lisa Blakemore-Brown
This paper discusses the issue of False Munchausen by Proxy.

This talk given to a group comprised mainly of professionals within the field of autism, was broadly separated into three sections:

1. Outline of my experiences and perceptions of errors of judgement in relation to false MSBP and examples of the types of problems which can be missed leading onto the

first grave error - an early erroneous assumption that the problems are 'induced or fabricated'..

2. Incidence - derived from Department of Health figures - of children placed on At Risk register each year - which must include the hidden figures of MSBP allegations
3. Processes which trigger and maintain accusations of MSBP and appalling effects of false allegations on innocent families

OUTLINE

Since working as an Expert Witness in a MSBP case in 1995, I am of the opinion that gross errors of judgement are being made (Blakemore-Brown 1997) at the very beginning of the process of 'identification' when the easy and increasingly widespread use of the term interweaves with shock tactics and processes of suggestibility.

Once that first gossamer breath of a rumour has been triggered - it can be impossible to turn back. (Blakemore-Brown 1998)

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Issues of very serious professional concern:

1. Mothers can find themselves targeted through concern for their child when they simply approach health, education and social services (paid by the taxpayer in civilised countries) for advice, assessments, diagnoses and interventions.
2. Fundamental real disorders such as Autism, ADHD and ME, and effects of medications on the developing foetus such as drugs for epilepsy given to the pregnant mother, significant prematurity, inborn errors of metabolism, extremely low birth weight etc., effects of multiple vaccine on vulnerable children and on child development are not well understood or even considered.
3. Professionals of specialisms other than the MSBP 'expert' are sidelined, ignored or their evidence distorted
4. Very basic errors of logic and basic statistics tied in with the pernicious use of unreliable and spurious 'profiles' appear to be woven into the development of MSBP theory building from the outset
5. Errors are compounded over time through:
 1. Processes of suggestibility and influence within large group settings - such as the multi-disciplinary group of possibly 27 people, which is much too large to reach consensus. Many 'lower status' individuals will be unable to express their opinion and will give way to the 'leading' and most 'eminent' opinion. They will also fear looking stupid if they are missing something others apparently can see -as in the story of the Emperor's New Clothes. Within such groups votes are openly cast as to whether 'abuse' is perceived to have occurred based on 'evidence' presented in seminar style from professionals who may have never seen the child or mother and opinions never heard by the family prior to such meetings. Such opinions can distort and influence what is ultimately actually seen.
 2. Easy professional boundary crossing practised by self-styled 'experts' and encouraged in others through one day 'training' in highly complex psychiatric and psychological issues presented as "forensic". These seminars have proliferated across the world since their beginnings amongst UK self-styled MSBP 'experts' operating first within the UK in the early 1990's and then within

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the US. A core group has driven the wagon which others now excitedly jump on in various countries.

1. Use of the Family Courts to validate spurious theory
 2. Use of the Family Courts' and Social Services' powers and resources to effect draconian practice
 3. Use of this apparent validation to influence Government which would now appear to embrace such thinking into sanctioned 'guidance'.
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1. Vast numbers of workers across the world being duped into less than professional behaviour by warped ideas presented to Courts and to Government as if based on robust scientific thinking and hard evidence
 2. The hijacking of kudos attached to the very real clinical awareness within psychiatry and psychology of very serious and rare somatoform disorders
 3. The kudos and acceptance of MSBP methods by naive professionals working in the field of factitious and somatoform disorders has allowed the self styled 'MSBP' experts to also bask in the warm glow of this kudos. Furthermore, they can create the impression that they are owners of some deep and meaningful psychoanalytic' knowledge, to which not all are privy (but they are - so this should trigger envy and profound respect in others) and that the vast and increasing numbers of 'MSBP' allegations reflect a hitherto unrecognised worldwide high incidence of factitious disorders caused by deep psychoanalytical influences - which only the MSBP 'expert' can possibly understand.
 4. When the MSBP 'training' leads to finding 'evidence' of such factitious disorders through methods described above, this leads to wild speculation that the individual is capable of, or has actually engaged in, life-threatening child abuse. It is this original assumption which shocks, distorts reasoning and justifies highly draconian action - and in some cases corrupt practice - and which ensures that mothers are presumed "guilty", through witch-hunt tactics, from the outset.

As this talk was prepared for an audience of professional peers working at the cutting edge of research and practice in Autism, I started from the premise that most of that audience would have an awareness of:

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1. How MSBP is determined through the research criteria
2. Acquired autism
3. A clear rise since the late 1980's in the incidence of a certain type of acquired autism - involving a tapestry of sudden onset bowel disorders, hyperactivity and extreme tantrums, loss of former language skills and evidence of motor impairments.

Despite the media and lay public opinion - it is NOT agreed that Munchausen Syndrome by proxy is an attention seeking disorder' - because in many cases of alleged MSBP this could not be ascertained - so the thinking shifts. Nor is it agreed that it is 'a form of child abuse' which Meadow, who thought this up, says it is (Meadow 1977) Confused? Not as much as MSBP accusers. They argue amongst themselves as to whether 'it' is a form of abuse OR a condition leading to abusing in this form. (Meadow 1995) They also argue about the 'profile'

of criteria.

For readers who are not acquainted with the world of Munchausen Syndrome by proxy, suffice to say that there is much controversy - even amongst the ranks of the self-styled 'experts'. In a Delphi Project undertaken at Auckland University (Craig 1998) it was established that there was only ONE criterion of those listed within a set of research criteria in DSM-IV (American Psychiatric Association) for which there was consensus amongst international "experts" - that a disorder is deliberately induced or fabricated in another person.

They chose between the following 'research' criteria.

DSM-IV Research Criteria for factitious disorder by proxy (Munchausen Syndrome by Proxy)

(Essential feature: the deliberate production or feigning of physical or psychological signs or symptoms in another person who is under the individual's care.)

A Intentional production or feigning of physical or psychological signs or symptoms in another person who is under the individual's care.

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- B. The motivation for the perpetrator's behaviour is to assume the sick role by proxy
- C. External incentives for the behaviour (such as economic gain) are absent.
- D. The behaviour is not better accounted for by another mental disorder

Differential diagnosis

(My comments in brackets and italicised)

Factitious disorder by proxy must be distinguished from a general medical condition or mental disorder in the individual being brought for treatment (the child). (? But they don't acknowledge or understand conditions such as autism, ADHD, ME, reactions to medications, vaccines, genetic errors etc. Nor have I seen the recognition that some people clearly have mental disorders - which explains the problem in the rare cases)

Factitious Disorder must also be distinguished from physical or sexual abuse that is not related to the goal of indirectly assuming the sick role. (? But there is no consensus that MSBP is about assuming the sick role)

Malingering differs from factitious disorder by proxy in that the motivation for the symptom production is an external incentive (? Such as services, benefits and 'expensive' interventions? But that is usually how the allegations start! - it's often what compels cash strapped departments to make such accusations - especially if crying MSBP brings in resources!.)

To add to the confusion, the theory is not scientifically enhanced by the additional use of a 'personality profile', notoriously unsafe in the forensic world, including child abuse (Howitt 1995) It is a 'moveable feast' which, when combined with secrecy and its reliance on powerful effects of suggestibility, has created a potent cocktail which drives it further forward and ensures it can ensnare anyone it chooses to ensnare, and also means it can never be proven wrong, never challenged - a crucial test of science. I've called it an 'autistic diagnosis' - you can't interact with it to challenge it.

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It's all things to all people. It can apply if you get on with the medics or you don't. It can apply if you are educated or if you are not. It can apply if you have a vast medical knowledge or if you don't. It can apply if you play with or pray for kids and it can apply if you don't. The presentation of such 'profiles' by eminent people easily leads to us lesser mortals accepting the theory - which is the intention of course. If a mother has a childhood history of abuse, she is a strong candidate, this caring society now punishing her twice over - even with no evidence of abuse' on her child. Just an assumption.

From my experience, many normal behaviours of anxious mums are misinterpreted as signs of this spurious 'profile'. Even being pro-active and empowered - checking out the symptoms seen in your child - is viewed with deep suspicion. Who doesn't search out information when their child is ill? What kind of a parent would they be if they didn't? Yet this very action has been used to accuse mothers of MSBP. Woe betide the mother who is computer literate - even though our UK Prime Minister said he wanted every person to have an email address - encouraging use of the Internet. In some cases features of Epilepsy, the effects of drugs for epilepsy, ADHD and the Autistic Spectrum are grossly misinterpreted in both parents and children. With appropriate recognition of autism and other disorders, support can be provided at a fraction of the cost of that within MSBP, and families would be helped not destroyed.

It has also been expected that the child would 'recover' once removed from the mother. If one follows the logic 'mother fabricated or induced ' the problem, one would expect it to go away once away from the mother.

Incredible as it may seem, I have evidence that information which would prove a mother's 'innocence' of spurious accusations has been ignored, omitted, removed or distorted to make the picture fit the frame of MSBP.

If evidence which seems to go against the profile cannot be hidden, the need for the particular criterion will be waved away.

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In my first false case the twins I assessed had been born at just over 26 weeks in the mid eighties. They were tiny babies with horrendous complications. The evidence that such premature infants go on to have developmental problems including attention deficits, motor and social impairments is now indisputable, but it was tossed to one side in this MSBP case. One of the early troubling issues for me was that the MSBP accusers initially totally denied that these children had such birth complications! They said this was 'what the mother said' and that I had been 'beguiled' by 'listening to the mother.'

Well, er, actually, I'd read the notes.....

Increasingly there is research which shows effects of medications on unborn infants. Mothers with epilepsy are at high risk of seizures during pregnancy, and must take medications. However, the last thing they want is to be blamed for the side effects on the infant of those essential medications. In one study, it was found that anticonvulsants taken during pregnancy resulted in a variety of features, which, in my experience, have been wrongly called 'child

abuse' - unless one wants to blame the medic who prescribes the essential medication for the epileptic mother. Well - the moveable MSBP feast will try to say that an epileptic mother is NOT epileptic -watching and scoffing whilst they are fitting. Hints of the medieval?

Details of some of the findings of effects in the infants of mothers taking epileptic drugs during pregnancy are outlined. (Moore et al 2000)

Problem

Percentage

Behavioural

81

Hyperactivity or poor concentration

39

Two or more autistic features

60

Learning difficulties

77

Speech delay

81

Gross motor delay

60

Fine motor delay

42

Glue Ear

33

Joint laxity

70

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The behavioural traits were poor social interaction, poor communicative skills, short attention

span, insistence on routines, hand flapping, gaze avoidance, aggressive or violent and no sense of danger.

The authors note that the 'high incidence of autistic type behaviours (81%) and hyperactivity (39%) was striking.' They go on to say 'There is currently a reluctance among health professionals to accept behavioural disorder as attributable to fetal anticonvulsant exposure. Wider knowledge of this association would relieve a great deal of anxiety among parents of affected children, who are sometimes told that either their child must have more than one disorder, or that they have inadequate parenting skills'.

This is just ONE example of many studies, which describe behaviours we recognise as autistic spectrum, which points to one particular causal route. There are many others. However, within MSBP the very presence of a behaviour is taken as indicative of child abuse.

Other 'likely culprits' are the strong and well researched genetic influence, viral infections, obstetric complications, medical problems and effects of interventions, exposure to toxic chemicals, vaccine damage etc. etc. Can ALL of these really be dismissed by the MSBP 'specialist'?

Given the increase of autistic and attention deficit problems in the last decade, often associated with hyperactivity, bowel problems and loss of skills, our advanced scientific community should put its energies into ascertaining why there is this population explosion, and no Government should encourage theories which make assumptions of abuse at first sight of a particular behavioural problem.

A recent UK Government consultation paper, Safeguarding children in whom illness is induced or fabricated (Department of Health 2001) unfortunately does just that. It further sanctions the use of such thinking by including reference to criteria which essentially describe autism (Jones and Bools 1999) but in this Guidance document the reader is worryingly invited to believe that the 'causes' of such features are based on abuse.

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This opinion is pure speculation and it beggars belief that it should be embedded within a guidance document which emerged from a Government Working Party, formed after the Griffiths Inquiry was alerted to the dangers of false allegations. This Inquiry, hearing evidence during 1999, some of it from myself relating to my first false case, reporting back in May 2000, recommended that a working party should be set up to ensure the 'correct identification' of MSBP. (Department of Health 2000b)

This working party signally failed to address the issues of false allegations. It starts from the premise that the diagnosis is sound and gives the impression that it has not even considered that it may not be, despite all the evidence provided to the Griffiths Inquiry. Not one article on false allegations appeared in the references and it would appear that not one member of the working party expressed concern about false allegations, either before or during their deliberations. It cynically uses the opportunity to promote MSBP as it is currently understood.

Articles are referred to which speculate that behaviours we would recognise as autistic are

actually signs of abuse. They are likely to influence vast numbers of young social workers and medical practitioners, teachers etc. across the world, to believe, for instance, that if a child does not like to be cuddled, it is because he recalls being smothered. Some of the assumptions are breathtaking, I'll give them that.

Many MSBP self styled experts seem unable to accept that if the disorders are continuing, a crucial criteria is not met, and so the original formulation of MSBP must be wrong - that the illness or disorder was deliberately fabricated and induced by the carer. Remember that this pivotal criterion is the ONLY one which a team of MSBP experts agreed on in a Delphi Project conducted in Auckland University. It should surely follow that IF the disorder continues after being dismissed, there has clearly been no MSBP type abuse.

In other words, the accusation was wrong.

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If accusers want to shift to say that carers or mothers caused a continuing serious disorder then this is a criminal accusation and must be proven through criminal courts using the high standard of proof, not just on the balance of probabilities following a good performance by a high profile 'expert' witness. Indeed, the furore which has built up around this 'diagnosis' has been fuelled by the suggestion -delivered as fact - that 'these' mothers will go on to kill children, as did Beverley Allitt. This has led to the justification of draconian action - such as removing children, preventing people from ever caring for children again and ensuring the MSBP tag is attached to their files, forever influencing the thinking of medics who read them. In turn this can affect the medical treatment which is necessary for children and adults.

The power of suggestion is grossly underestimated. In a Canadian study, it was shown that even when a person KNEW that information had been suggested to them - 'they may still incorporate it into their own recollection of events'. So we can even recall false events and truly believe them. (Higham, P. 1998) This has implications not only for the few families who can be proven to have 'falsified' evidence - but also for the workers who really believe what they have been told is the truth.

Astonishingly, the Consultation Document also invites us to set to one side the criteria that disorders go away once children are removed from the MSBP abuser -the perpetrator - by embracing the findings and assumptions from another study by Bools et al (1993). Far from disorders and problems going away once children were taken into care, they actually found ' a range of emotional and behavioural disorders, and school related problems, including attention and concentration and non-attendance."

For years there were attempts to hide how the children were developing or behaving in care, to avoid having to admit that the problems had not actually gone away..... However, a number of foster and adoptive mothers are now being accused of causing the problems through MSBP type abuse - so it's open season. The MSBP experts' moveable feast explanation is that we should now realise that 'the abuse' probably has a life long impact.

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However - perhaps there was no abuse' by the carer, perhaps the real disorders were actually

not recognised and the child and family not supported, leading to a spiral of system abuse which will certainly have a life long impact on the child.

In its current form this Document is highly dangerous to families and children with autism and other misconstrued disorders and to workers influenced by this thinking. There have already been letters in www.bmj.com which clearly indicate that the writers considered the Guidance to be the final version.

Summary of how errors are made - and their effects

1. Increasing number of mothers who try to establish what is wrong with their children and who try to secure support./resources/interventions for them are scrutinised using MSBP thinking
2. Starting point over focus on the spurious profile of the mother colours reasoning and starts rumours. The MSBP theory - building on the basis of this 'profile' is akin to a Type 1 statistical error - that there is an association between the variable of mother 'profile' and the variable of potential to induce/fabricate illness and harm/murder child. Therefore, when a 'profile' is found it is assumed that any illnesses/behaviours have been induced or fabricated.
3. There is no real effort to ascertain whether illnesses/disorders are real, indeed there may be sterling efforts to hide such realities, but if it cannot be disputed, this is sidelined as irrelevant.

INCIDENCE

Whilst the Working Party was deliberating, I was preparing the talk for Durham. I decided it would be helpful to have some statistics on the number of MSBP allegations over the years, to back up my initial prediction that this would become an epidemic if not stopped. Over the years this has been proven to be the case, but secrecy in the system has allowed details to remain hidden - until this time, when it is

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obvious to anyone working with children and families that there is a now a very serious problem.

Whilst most of those falsely accused are still struggling to get their cases to Appeal Court, evidence from support groups for parents of children with a variety of disorders has suddenly noted a mushrooming of this allegation. One social worker said she knew of 70 cases - in one patch. One mother was threatened that if she would not allow her child to be in a study, she would be accused of MSBP. Another woman in the same road had been threatened in the same way. The one who refused was accused of MSBP.

I expected the Working Party at the Department of Health to be able to give me the figures. I naively assumed that if they were looking at false allegations - which one would expect them to do given their brief to ensure 'correct identification' - they must surely first want to see the extent of the apparent problem. What I had not realised at that stage was that they were avoiding looking at false allegations, instead cynically using the chance to promote the use of MSBP and sanction its methods of 'identification'.

From what I could gather the working Party were not easy to speak to, although I was told that I needed to speak to Jenny Gray - who was never available.

The Department of Health very kindly gave me all the figures pertaining to children on the At Risk Register. When I looked at the year on year figures (of children placed each year) it was very clear that there had been a year on year RISE in the children placed on the Register since figures were first kept in the year 1995. Within those figures were hidden the MSBP allegations, under 'Physical' or 'Emotional' abuse.

Astonishingly, the figures for Emotional Abuse had almost doubled in five years, from just over 3000 to just under 6000.

As Chairwoman of Promoting Parenting Skills, a group of psychologists in the UK, I know that the understanding of parenting issues has IMPROVED vastly over that

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time period, and yet we were invited to believe that over the same period of time, increasing numbers of mothers were engaged in the most appalling kind of abuse against their children.

BRIDGE OF SIGHS

'Processes' within MSBP accusations lead workers and mothers and their falsely accused families across bridges hitherto uncrossed. The beguiling emotional impact is extreme and helps to maintain the attitudes of false accusers.

Using an acronym I attempt to highlight some of the processes which result in the terrible actions of workers

Suggestibility, Shock, Scandal

Ignorance of real disorders/Ignoring real disorders/Interference with evidence -making picture fit the frame

Gross errors of judgement/Groping obscenely at innocent mother

Hyperbole/Hysteria/Heresy

Secretive/Sectarian/Sensationalist

Using the same acronym - how it affects innocent families Shocked and horrified

Impossibility of proving innocence Gross injustice

Humiliated/Hurt/Helpless and Hopeless

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Sinking into desperation and very serious illness **POSTSCRIPT**

If readers consider that my opinions are based on ignorance, exaggerated or malicious, they may like to consider the now undisputed rise in such accusations and the increasing public awareness of false cases (Face the Facts Radio 4 July 2001) Earl Howe, Shadow Spokesperson for Health in the House of Lords has tabled a debate on the issue on October

17th 2001.

For the public record, from the outset I have diplomatically raised my concerns to Government about the dangerousness of this accusation and the methods - to no avail.

I only feel saddened that what I said is being proven to be true.

Readers might like to consider the effects of the truly ignorant assumptions about autistic behaviours reflecting 'abuse' when these and other pearls of wisdom are 'taught' in ONE DAY seminars to ANYONE working with children and families with a credit card or cash. Think about that rumour effect when even play leaders are 'taught' to diagnose MSBP.

These types of seminars have occurred for some years now in the UK, but largely 'secret'. Now, thanks to the success of these early secret meetings and the validation of MSBP in secret courts and now Government documents, the MSBP theorist operates openly, their success providing them with a renewed vigour and sparkling self-confidence. Passing the tablets of stone over to other countries has been long associated with the UK, and we have usually been proud to admit that we have influenced other countries across the world.

Below is a quote from adverts for a forthcoming 'roadshow' in Australia and New Zealand on MSBP by a self styled US social worker, herself influenced by the UK

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experts during the nineties. She has just 10 years in social work, is only 'scheduled' to receive her MA in Psychology later this year..... but is considered an international expert on MSBP who is 'cogent and compelling'. They usually are -that's part of the problem.

So sure now are these people that they can promise you that:

AFTER ONE DAY 'Participants will be able to:

Explain/ differentiate among factitious disorder, Munchausen Syndrome and MBP maltreatment

Recognise common MBP suspicion indicators

Explain MBP confrmation/disconfirmation process basics

Explain the importance and role of a multi-agency/multi-disciplinary team throughout the MBP case process and will be able to state step (sic) in organising and planning an initial team meeting

Discuss how and when to interview(confront) the perpetrator for the first time after the MBP confirmation

Explain the activities and decision making regarding MBP victim out of home placement

Describe safe victim access and guidelines

Discuss key elements and activities involved in court preparation and presentation

Explain and recommend MBP case plan elements/activities to be completed prior to recommendation of unsupervised access or reunification

Explain the role of the mental health professional regarding MBP related cases, strategies for therapist selection and MBP related goals

Explain issues related to MBP case plan'

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Virtual Reality and People with Autistic Spectrum Disorders: Informal Observations from the AS Interactive

Project. Sarah Parsons* and Peter Mitchell

School of Psychology, University of Nottingham, UK. :

*Corresponding author lpaxis@psychiolotiv.nottingham.ac.uk Abstract

AS Interactive is a multidisciplinary project comprising researchers from the University of Nottingham and the National Autistic Society. The main aim is to improve social skills amongst people with Autistic Spectrum Disorders (ASDs) using Virtual Reality Technology. At this early stage of the research, the first step is to see how people with ASDs use the technology. This paper outlines the rationale of the project and some preliminary results from a group of 13 pupils with ASDs aged 13-18 years. Participants had the opportunity to practice basic skills in a 'training' virtual environment, which was presented on a laptop computer and navigated with a joystick. Participants then used a Virtual Cafe in which they had to perform a number of simple tasks, such as finding a seat and ordering food from a menu. Initial observations suggest that participants in this group were motivated and extremely

comfortable with the technology; they experienced few difficulties completing the required tasks. Participants also seemed to understand the virtual environment as a representation of reality. However, preliminary findings suggest that individuals with autism might lapse into infringing personal space in virtual environments.

Introduction

The name of the AS Interactive project reflects our target participants and the nature of our approach to developing social skills. That is, using new technology