

### The Story of Charin

### The Autism Awareness Year Campaign

### By Ivan Corea

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The session focused on how to work with others and motivate people – the session was led by Ivan Corea, Fellow in Leadership Development of the King's Fund.



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#### THE STORY OF CHARIN

2002 is Autism Awareness Year. Prime Minister Tony Blair has personally endorsed the year. What started off as a small acorn of an idea in the front room of Ivan and Charika Corea in Buckhurst Hill Essex is now the largest ever movement for autism in the UK – 900 organisations have come on board as partners of Autism Awareness Year. 153 members of parliament signed an early day motion backing the campaign. Ivan Corea shares his story....

Charin was born around 4 a.m. in an East End hospital amidst the food stained walls, the apathy, the stresses and strains of the doctors – the first objective of the hospital seemed to be to cut costs. When this little bundle of joy was placed in my arms ((his mother was still unconscious after the caesarean operation) I could only offer a prayer of thanks to God for this wonderful gift of life.

Charin seemed to develop normally – he smiled at three weeks, he babbled at 9 months, he walked at one year. He loved looking at books, he enjoyed listening to music, and he started doing complex puzzles at a very early age.

Suddenly it all went horribly wrong. At eighteen months he appeared to stop babbling. It was extraordinary. A few months before it was as if he was on the verge of talking – here we were with a baby who went into his shell and slammed the door on the outside world.

We took Charin to the Rectory Lane Health Centre in Loughton, where, a Sri Lankan paediatrician Dr. Rudran diagnosed Charin as having pervasive developmental disorder – which refers to a whole group of disorders characterised by delays in the development of multiple basic functions including socialisation and communication.

The renowned Consultant Paediatrician, Dr. Gillian Baird of Guys Hospital in London and paediatrician Dr.M.Ali in Loughton later confirmed this diagnosis.

Symptoms of PDD include severe communication problems such as understanding language; difficulty to relating to people, objects and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings, and repetitive body movements or behaviour patterns.

Autism, the experts suggest, a developmental brain disorder characterised by impaired social interaction and communication skills, and limited activities and interests, is the most characteristic and best studied PDD. Other types of PDD are Asperger's syndrome, Rett's syndrome, childhood disintegrative disorder and others.

Autism is a neurodevelopmental disorder – all of us have neurons in our brains to process thought, they need to fire in the correct order – in the brains of autistic children these neurons don't fire at all or they just misfire.

That is why you cannot give an autistic child complex commands – everything has to be kept well and truly simple.

The fact that Charin could be autistic devastated us – it was like a thunder bolt that hit our family life, our marriage, our whole world. I t was also the beginning of a protracted battle with my local Council to get a proper structured educational program and speech therapy for Charin.

Initially we refused to accept the diagnosis – there were no cases of autism in our families – a hundred and one questions went through our minds – was it the MMR vaccination, was it the foetal distress? We were in turmoil and sadly there was no local support for parents like us.

The strain was enormous, almost to breaking point. So were the financial implications, my wife had a leave work, as our son needed full time care. Few understood the situation.

We found the Internet to be a real boon — we surfed the web and found a great deal of information on PDD and Autism. Parents from all over the UK and from the United States e-mailed us with information and support. People telephoned us from all over London.

We were soon sharing information and research. Even the Autism Research Institute in San Diego got in touch with us. The Internet was a heaven sent gift – we were able to read up and digest information on

Autism and its causes. The National Autistic Society in London were also very helpful.

Although we were physically, morally and spiritually exhausted – we received tremendous support from our church. Many a time we faced depression but we were determined to do something for our child My wife Charika's indomitable spirit was a great strength to me – it was difficult for her – she was with Charin 24 hours a day. At least I was meeting people as a teacher and a journalist.

We soon found there was no cohesive national policy on autism – from both an education and health point of view. Some LEAs were absolutely brilliant while others kept the money in the bank and would not shell out a penny for autistic children.

Cost cutting was the name of the game. There were many places and therapies – some parents sent their children to the Boston Higashi School to follow the Daily Life Therapy Program, there was the Sonrise program, Lovaas, TEACCH, ABA, and PECS.

It took three months for Charin to be found a placement by Essex due to red tape; the speech therapist came home and gave us no support - all she seemed to do was assessment after assessment with no real advice or any plan of action — a speech therapy program for Charin was non-existent; the school had to go through changes themselves and learn about different strategies to educate an autistic child.

We were convinced that it is through early intervention that Charin could be helped – it is through education, education and education that we could reach out to Charin.

We found that we were not alone in doing battle with the local LEA. Many parents across the UK were in the same position as we were – cost seemed to be the overriding priority – the local health authority even refused to pay £50 for a urine test undertaken by the University of Sunderland to check if Charin suffered from allergies.

It was exasperating and frustrating – you pay your taxes, you do work for the community and you expect some support from the NHS and the educational authorities when something happens to your own children. You do not expect to be stonewalled by a world of cost cutting, reluctance and apathy.

However as parents who come from a minority ethnic community we were determined to overcome the barriers placed before us. We are not going to give up on our child. At the same time we realise there are many more parents from ethnic communities across the UK who are confused, they do not know where to turn to or where to seek support.

We were also convinced that it is through inclusion – in a mainstream school with the support of a specialised teacher trained in dealing with autistic children that Charin could be helped. He also needs a specialised program to help him communicate.

Former psychologist, Sue Baker, a consultant in the Picture Exchange Communication System (PECS) came home and conducted a training seminar for the team working with Charin – including his teachers.

PECs is a system developed by Lori Frost and Dr. Andrew Bondy from Delaware in the US. PECS aims to provide children with an effective and functional method of communication.

PECS uses picture symbols and children learn to construct sentences and more complex communications enabling them to be more effective communicators.

Through this specialised program children are taught to initiate communication within a social context – they learn to exchange - Charin has already taken to the system and the early signs are very encouraging.

Charin has been greatly helped by music therapy sessions at the world famous Nordoff-Robbins Centre for Music Therapy in Kentish Town. The highly respected Jacqueline Robarts, a research fellow with City University has taken Charin on together with Donald, a second music therapist - we see a real change in Charin after these sessions also aimed at encouraging communication through music.

Sting and a whole host of musicians support the Nordoff-Robbins Centre – they lead the field in research on the subject.

'Music is therapy and has always been so,' said Sir Yehudi Menuhin, we can see the link between healing and music – Charin is being helped through the power of music – he hated it at the start, now he kisses the music therapist and we see real progress.

Another institution that has helped Charin so much is the Osteopathic Centre for Children in Harley Street. The OCC was backed and supported by the late Diana, Princess of Wales.

When Charin first went to the OCC he squirmed, he wriggled, he screamed – he hated the cranial osteopathy but now when he goes there every three weeks – he is relaxed, he has made friends with two osteopaths – Gabby and Jo – he even allows them to carry out the regular treatment to his stomach and diaphragm to calm him down and to tackle the trauma he faced at birth.

The transformation in Charin after these sessions is amazing. He is more relaxed at home and it helps us to communicate with him and he with us.

There have been recent moves to help families with such children – the NAS have launched *the Early Bird Program* to support parents. Cherie Blair, wife of the Prime Minister recently launched an advocacy scheme with the NAS to help parents of autistic children – on the legal side.

Recently an *All Party Group on Autism* was set up in the House of Commons aimed at supporting autistic children and lobbying on their behalf – we welcome this move. Autism is on the increase and much more needs to be done to support autistic children and to help them cope with this condition.

We wrote, we lobbied, we spoke at meetings including the Labour Party Conference. Many many MPs wrote back to us to tell us that there postbags were full of letters from parents and carers who were having smiliar problems with their autistic children.

The Medical Research Council recently stated that the MMR was safe, what we want to know as parents, what has caused Charin's autism. We are urging the government to launch a major research project on the causes of autism.

There are 520,000 autistic people in the UK, numbers are set to rise dramatically in 5 years time – it will be a real emergency, a BSE type crisis, will the government be prepared for such an emergency. Where are the support systems. There is a huge shortage of specialist teachers trained in dealing with autistic children and specialist speech therapists.

I am grateful for the support of black and Asian peers and members of parliament among them – Diane Abbott, David Lammey, Oona King,

Piara Khabra, Dr.Ashok Kumar, Marsha Singh, Baroness Pola Uddin, Lord Dholakia who all supported Autism Awareness Year.

Prime Minister Tony Blair and Cherie Blair have personally endorsed Autism Awareness Year.

I would urge members of the public, institutions and organisations – write to your MPs about Autism Awareness Year. Autism is rising even within the minority ethnic community. We need support. The time for action – is now.

Please access the official website — <a href="www.autism-awareness.org.uk">www.autism-awareness.org.uk</a> for more information on Autism Awareness Year. The British Institute for Brain Injured Children and the Disabilities Trust together with the National Autistic Society and 400 organisation have declared 2002 — Autism Awareness Year.

Or telephone Pam Brooks on 01278 684060 for information.

# AUTISM AWARENESS YEAR 2002 - the story so far... Autism 2002

#### How did Autism Awareness Year start?

In May of 2000, BIBIC was approached by a man, Ivan Corea, whose fight to get provision for his autistic son had led him to write to many charities who worked with this condition. His letter arrived at a time when we were noticing a marked increase in the number of autistic children coming through our doors with families all saying the same - they just couldn't get the help they needed in their locality; they were fed up with their children being labelled 'naughty' and that few seemed to understand their child.

Ivan's letter pleaded for someone to take up the challenge and help him declare 2002 as a year focusing on autism. He had already achieved remarkable success in his drive to get this up and running, having worked on politicians to support an Early Day Motion in parliament in Westminster declaring their

support for the year. 153 MPs signed the motion: an excellent start. What he needed now was someone to actually declare the year and act as a facilitator to make it happen.

Ribbons are

available at a

of £1 each

Autism is not the only condition we work with but we wrote saying that we would certainly support him in this venture. We bit the bullet and made the announcement.

#### What is Autism Awareness Year all about?

In the meantime, Ivan had been busy doing what we now know he does best - lobbying: we had a call from The Disabilities Trust wanting to know if we needed a partner in the facilitation process. They were welcomed with opened arms and together we planned a mission. Part of our aim for the year was to work with other voluntary sector organisations. We knew that there was a lot of good work going on already and that if we could pull it all together under one banner something could really be achieved.

We wrote to other organisations setting out our vision and inviting them to express an interest in the year and to attend a partners' meeting at Knowle Hall, BIBIC's headquarters. Twenty were able to attend. Aims and objectives were discussed animatedly, issues of funding investigated and an events plan mooted. By the end of the meeting we had an impressive Autism Awareness ribbon to use from an organisation called Allergy Induced Autism and plans for partner activities UK-wide.

Whilst organising the partners' meeting we had a call from a charitable trust called The Shirley Foundation. They had heard about the year, and we were invited to apply for a grant! This 10 was the exciting breakthrough that we needed to fund an inaugural strategy and policy conference pitched at key decision makers and those holding the budgetary power in national and local government posts.

The Shirley Foundation agreed the proposal. This year was really going to happen!

#### What makes it different from other awareness-raising cambaigns?

Most awareness-raising campaigns are run by one organisation, usually a large one with a measure of autonomy on how the campaign will be run. The exciting thing about this one is this is a year for ALL those who work in the field of autism to get their message across under the collective banner of Autism Awareness Year and all active partners are involved in the planning process.

suggested donation To date, we have over 300 organisations, large and small from England, Wales, Scotland, Northern Ireland and Eire. participating in this year of awareness-raising - and that figure is still growing. Each keen to play their part in helping others to understand the issues surrounding autism; all keen to address the misconception that all autistic people have a hidden talent and genius and to bring appropriate help and support into their community.

#### Why is it important to have this year?

It is believed that there are around 520,000 individuals in the UK with autism. There is no central register so no one can be really certain. It is believed by many who work within the field of autism, that in reality, this figure could be as much as doubled as many are still undiagnosed and are unknown to the authorities. 33% of adults with autism have no social involvement. Only 12% of those diagnosed with autism are able to work. Autistic Spectrum Disorder (ASD) often falls into the gap between mental health and learning disabilities. Only 38% of people with autism and Aspergers have a community care assessment, and of those that have, only 16% were actually offered one; others had to ask or fight for one. Only 45% of those assessed received the services specified in the assessment. 49% of adults with autism or Aspergers are still at home with their parents.

The average lifetime cost of supporting an autistic person has been estimated at £2.9 million. That excludes the loss to the economy as a result of autistic people who cannot live independently and earn their own living. The total cost to the economy is about £1 billion a year.

#### What has been achieved since the inception?

We have only just started this year-long campaign; there is much to do and we have no doubt at all that it will grow in stature as the year progresses. As one person voiced in a meeting recently "we have one chance at this - it is something we have all talked about for years. Now we have that golden opportunity, we must not waste it"

153 MPs signed an Early Day Motion for 2002

300 organisations working together Full coverage of the UK and Eire A debate in Scottish parliament January 6 2002 was Autism Sunday A breakfast meeting at the Labour Party Conference in 2001

An Adjournment Debate on AAY 2002 Full support from the Prime Minister Funding for 9 Regional seminars, Inaugural conference at the Kings Fund A ribbon to symbolise the year Increased coverage in the media of this subject Opportunities for shared fundraising activities New partnerships and working relationships Expansion of partnership to include professional bodies

An extra £2.5m towards research into autism.

#### **Attention Parents**

If you have an autistic child we have cards that you can give out to people when you are out and about. These cards politely explain that your child is doing the best he/she can at the moment and that you are not being a bad parent.

These are particularly useful if you feel that someone is misinterpreting your child's behaviour.

We have a small supply and are happy to distribute them while stocks last.

Tel: 01278

684060

This child has autism He/she is not being naughty and we are not being bad Children with autism can often behave in an unpredictable manner because they find it hard to cope with many everyday situations. They are quite simply doing their best. Please be patient

#### Policy and Strategy Conference

February 14 was significant in the calendar of events for the year, with a conference which was hailed by professionals as an important event to launch the year.

included: Ros Blackburn and Richard Exler both speakers affected by the condition, Ivan Corea, Suffolk Social Services Joint Commissioning

Service, Dr Stephen Ladyman (chair of the All-Party **Parliamentary** Group for Autism)

and Jacqui Smith, Minister for Health. who delivered the keynote speech.

The government had afforded it such importance that they used the conference to announce a further £2.5m to be made available for research into the condition and the Prime Minister requested that we feed key points directly back to

Workshops were facilitated by many eminent contributors including Baroness Blatch, Professor Lingham and Dr Paul Shattock. They covered subjects such as causation, the Education Code of Practice, ethnicity and therapeutic support.

Feedback has been phenomenal and we are certainly pleased with the event as a





home

### welcome to www.autism-awareness.org.uk

#### "Ages of Autism"

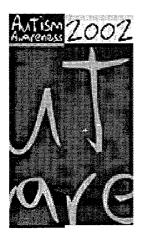
Strategy and Action Feedback Conference
21 November 2002

The Royal Horticultural Halls, London SW1

#### Partners and supporters resource area - click here

### Sanath Jayasuriya Captain of the Sri Lankan Test Team

adds his support for Autism Awareness Year 2002



#### **AUTISM AWARENESS VIDEO:**

Click here for more information on the video and how to order a copy

#### **Prime Minister Tony Blair**

adds his support for Autism Awareness Year 2002.

#### Mission Statement:

To raise awareness, through voluntary sector partnerships, of the issues surrounding autism and to influence and inspire action to facilitate the changes needed to services and attitudes to autism.



One common misconception about autism is that is is a condition that only affects children. The truth is, children with autism grow up to become adults with autism. There is a far greater number of adults (18+) with autistic spectrum disorders in the UK than there are children.

#### Aims and Objectives of Autism Awareness Year 2002:

- To target the political, educational, health and social care decision and policy makers and primary budget holders
- To improve awareness within the relevant statutory sectors giving them much needed knowledge of what autism is, its effect on the individual concerned and what can be done to bring about improvement
- To inspire LEA's and NHS Trusts to take a long hard look at autism and to develop and implement clearly defined strategies to deal with the increase in this condition
- To influence the Government to stop postcode lottery for education and health care therapies
- To achieve the ultimate benefit for parents with children who are autistic of being able to access needed services in their local community
- To work towards inclusion of those with autism at all levels.

Events connected with raising awareness about the condition will be held across the UK.

**2002 Autism Awareness Year** will be launched by the <u>British Institute for Brain</u> <u>Injured Children</u>, <u>The Disabilities Trust</u>, ratified by the <u>National Autistic Society</u> and a host of autism related organisations. 153 members of parliament of all parties signed early day motion 103 in the House of Commons in the Palace of Westminster backing the proposals. It remains to this day the most successful EDM connected with Autism.

Click here for a current list of partner organisations who have provided their backing for Autism Awareness Year 2002

If you would like to receive updates on Autism Awareness Year 2002, fill in our on-line form here

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www.autism-awareness is hosted by <u>The Disabilities Trust</u> / <u>BIBIC</u>. UK Registered Charity Numbers: 800797 and 1057635

#### public endorsements

Rt Hon Tony Blair MP
Rt Hon Estelle Morris MP
Rt Hon Iain Duncan Smith MP
Rt Hon Jane Hutt AM
Romesh Gunesekera - Author
The Rt Rev'd & Rt Hon Richard Chartres DD FSA
Shyama Perera - Author
Sanath Jayasuriya



#### 10 DOWNING STREET LONDON SW1A 2AA



Rt Hon Tony Blair MP The Prime Minister February 2002

Autism is one of the least understood but most frightening and difficult of conditions. I welcome initiatives which aim to improve our knowledge and understanding in this area. People with autism lead isolated lives. Their social and communication difficulties place great stress on their families. It is important that we should all be sensitive to their needs.

Autism Awareness Year has an important contribution to make. I am pleased that Health Minister Jacqui Smith will represent the Government at the opening conference on 14 February. We will listen carefully to the messages which emerge.

I am also pleased to note how much activity has recently been stimulated on

autism. This includes the independent "National Initiative on Autism: Screening and Assessment" which is due to report in 2002. The Government has also been active. The Department for Education and Skills will be issuing good practice guidance on autism in the coming months. Two reports commissioned by the Department of Health - from Dr Tony Holland on Asperger's Syndrome and from the Medical Research Council on the Epidemiology and Causes of Autism - have also recently been made available. Both of these are helping to improve our understanding of autism.

I very much hope that Autism Awareness Year will build on this work as well as being able to make its own distinct and complementary contribution. I wish it every success.

Rt Hon Estelle Morris MP Secretary of State Department for Education and Skills

1 my Blair

I am firmly committed to making a difference for pupils with special educational needs. I want all pupils - including those on the autistic spectrum - to have the opportunity to achieve their personal potential. For complex spectrum disorders like autism it is essential that children are treated as individuals. Their needs must be assessed carefully to ensure they receive the right provision.



HOUSE OF COMMONS
LONDON SW1A 0AA

Rt Hon Iain Duncan Smith MP Leader of the Opposition December 2001

**AUTISM AWARENESS YEAR 2002** 

Most of us have heard of autism, but few of us perhaps really know much about it. Few of us recognise the varied range of behaviour it covers, or appreciate the different problems it can cause.

Around half a million Britons are autistic. Their families and those who care for them are also affected.

Autism Awareness Year is therefore greatly welcome. The Disabilities Trust and the British Institute for Brain Injured Children do marvellous work for people with autism and I wish them every success.





# Rt Hon Jane Hutt AM The National Assembly for Wales December 2001

I was interested to learn that The Disabilities Trust in partnership with the British Institute for Brain Injured Children is planning an Autism Awareness Year for 2002. I do hope that you have a successful year and that the events organised succeed in raising people's awareness of autism issues.



Romesh Gunesekera Author February 2002

I wish the organisers of 2002 Autism Awareness Year success in the campaign to increase awareness of the problems faced by those with autism, and their families. I salute their courage, and support the call for a full range of support services to be available to meet their needs across the UK.



#### THE BISHOP OF LONDON

### The Rt Rev'd & Rt Hon Richard Chartres DD FSA February 2002

I know from personal contacts that autism is a most baffling and mysterious condition. I know how vulnerable and anxious the most loving carers can be as they live with autism and try to protect and help. I commend the initiative that has lead to Autism Awareness Year and pray that it will result in increased understanding and an enhanced sense of urgency in responding to the needs of those with autism.





#### **Shyama Perera - Author**

It was after having children that I learned of the high incidence and complex nature of autism. Within my own small group, two toddlers were diagnosed autistic. It impedes their progress, independence and pleasure, while placing untold demands on their families. Any campaign that promotes awareness of autism deserves time, support and action.





Sanath Jayasuriya Captain of the Sri Lankan Test Team

I am delighted to send this message of support to the Autism Awareness Year campaign launched by Ivan and Chrika Corea, The Disabilities Trust BIBIC and 800 other UK organisations. I am told that there are 520,000 autistic people in the UK and there are rough estimates of 30,000 autistic people in Sri Lanka. We still don't know much about autism and how it affects the lives of children and adults. I fully support this awareness campaign launched by Ivan Corea. I met their son Charin before his diagnosis when we visited the UK in 1996 as World Champions and in 1998 in Buckhurst Hill. My best wishes go out to Charin and the thousands of autistic people in the UK and Sri Lanka.

We are dilighted to be playing a 3 Test Match series against England and we hope it will be an enjoyable summer of cricket for all cricket fans in this country.

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## Working with Others

A Personal Tale:

## The Story of Charin

Autism 2002 – Autism Awareness Year

### Main characteristics of a project

- It is an instrument of change
- Has a specific identifiable start and finish
  - Has a specific aim/goal
  - Results in something being delivered
    - Is unique
- Is the reponsibility of a single person or a team
  - Involves cost, resources and time
  - Uses a wide variety of resources and skills

### Personal Qualities of the Project Manager

- Motivating
- Delegating
- Communicating
  - Leading

The key to motivating people is achieving a degree of alignment between their personal objectives and the project objectives. You must be able to show that people will actually get what they want by doing what you want

### **MOTIVATION THEORIES**

Maslow – A hierarchy of needs ranging from physical to existential. Professor Abraham Maslow observed that the need we feel most strongly determines our behaviour. Motivation comes from striving to feel a need.

Herzberg – Distinguishing between what motivates and what de motivates

Pope – 'Deadly Sin Theory'; people are motivated by pride, lust, anger, gluttony, envy, sloth and covetousness.

Different people are motivated by different things

**Motivating Factors** 

**Quality of Work** 

Sense of belonging

Feeling of involvement

Sense of achievement

Recognition of success and effort

Opportunity for development and progression

Fulfillment of skills and abilities

**Increased responsibility** 

### How to motivate others

- Communicate your vision and goals openly and honestly
- Involve your team in preparing their own objectives to their work
- Help your team to acquire new skills
- Trust them and give them responsibility to respond to various challenges
- Be fair in your treatment
- e Facilitiate creativity
- Share all information with your team

### **Networking**

- How well connected you are determines your access to those with money, the most power and influence, opening up future business opportunities for and your team. A low profile carries a high cost
- Anyone can be a good networker but many of even brightest individuals fail to make the most of this powerful resource. Some believe they are too important.
- The most effective networkers are 'givers' They find ways to become more valuable to others by giving favours, business leads, referrals, testimonals and helpful ideas.
- At the end of a networking event they judge their success not on how many cards they have given out but how many they have collected and the potential relationships they have created.
- Ask how useful iss this person to my entire network NOT What can this person do for me.

\* Promise approach of meeting new people

#### do's and don'ts of networking

Bet out more! Attend more industry functions and general business events. You can't grow your network if you don't meet new people.

Decide that you will stay until you have met and connected with a pre-determined number of people. Start with just one or two - as your confidence and success grows, build it up to five or six. [point]

Stand up. Sitting down at a networking event doesn't work.

\_isten more carefully to others' names. Repeat them until they are odged in your brain. If you didn't catch their name ask them to repeat t, rather than letting it go.

Focus on finding ways to be of value to others - forget, initially, what's in it for you. Do this by offering opportunities to others - information, referrals and recommendations with little or even no desire for a return favour. Offers with strings attached are not offers.

In order to help others, you need to know what they want. To find out, ask lots of non-threatening questions.

Follow up on any promises you make. [point] Adopt the "Rule of four" by re-connecting with four people every day who you may not have spoken to in a while.

Decide whom you want to get to know in the next 12 months.

### don'ts of networking

Don't say you'll attend something and then forget or change your mind about going.

Don't spray your business cards around like a tom cat.

Don't introduce a female colleague by her first name only, when men are so often given the full works - full name, job title and why they are so successful or important.

Do not contact others only when you want something - people notice.

Don't forget to ask for a delegate list in advance if you are attending a seminar or conference. Use that list to target those you want to meet.

Do not dismiss support and junior staff such as secretaries, assistants, waiters and waitresses, security guards and those who deliver the internal mail because they can all be huge allies, or your biggest enemies. Spouses also have far more power and influence than some imagine. Nurture them. Get to know them as people. Look after their interests and they will recognise and reward you by providing access to their decision making "superiors".

aniel Soanes speaks to a couple who have an autistic son and ho are working to raise awareness of the condition

n a world of his own

VISIT to a McDonalds restaurant ended in embarrassment for a young Buckhurst Hill couple when he manageress asked them to take heir son out of the play area. Our-year-old Charin Corea had been nouting and thrashing about, and the ostily polite manageress was worried ther children might be injured by their hyperactive" and badly-behaved boy. "Things like that happen all the time," hid his mother, Charika. "I've got used o people staring at us wherever we o."

But Charin is not badly behaved, iolent or stupid: he is autistic. He idn't understand why the manageress ranted him to stop shouting or running round. As far as he was concerned ich behaviour was perfectly normal. The term "autistism" covers a broad pectrum of disorders, the common nemes of which are an inability to elate to the world as others know it nd difficulty communicating. Charin, or example, can't understand why he is ot allowed to eat food from other eople's plates. The only way such a ocial nicety can be explained to him is arough visual aids, such as cards, and ctions.

"Bringing up any young child is hard vork," said Charika. "But looking after n autistic child is a real challenge. even worse, we've started losing a lot of our friends. People think he's just a raughty boy."

The biggest problem came when Charika and her husband Ivan tried to ind a school which would accept their on. Many turned them down, fearing Charin would hold back lessons and disrupt other pupils. In fact, in common with all autistic children in mainstream schools, Charin will be provided with a full-time carer and his progress will be measured separately from his fellow bupils. The specially-trained assistant would act as a medium to help him get on with other children and his teachers and try to ensure he kept up with as nany lessons as possible.

Charika said: "It's vitally important that children like Charin go to normal schools so they can imitate normal behaviour. If they are all locked away in special schools they will always be shunned by society and then what chance will they have?"

Charika and Ivan believe the only way to persuade schools to accept autistic children is to increase



Charin Corea is misjudged because he does not see the world as others do

awareness of the condition.

"We face a lack of understanding about autism from almost everyone we come up against," Charika said.

The couple have decided that 2002 should be declared Autism Awareness Year, an idea they have already shared with the Prime Minister, Tony Blair, and the Education Secretary, David Blunkett, among others.

Ivan said: "The campaign started

when I found that even healthcare professionals and teachers did not know much about autism. Our son has had to suffer unfair discrimination and it has been such a struggle to overcome a catalogue of neglect, apathy and incompetence.

"By declaring 2002 Autism Awareness Year, I hope to increase the profile of autism and galvanise education authorities and NHS trusts to take a





long hard look at the condition."

Most people's only awareness of autism is through the character Dustin Hoffman played in the film Rainman, a childlike adult with an unshakable obsession for lines from films and for numbers.

Ivan said: "That film is quite an accurate portrayal of one type of autism. But Charin's condition is completely different, and it is vital that people know more about the whole spectrum."

The couple have urged MPs to put their idea for an Autism Awareness Year before Parliament and are also asking members of the public to write to their MPs and to the Prime Minister asking for the idea to be given high priority.

Ivan said: "This is my vision and I need your support to make it a reality. We believe Charin is a gift from God

and he's very special to us. But there are at least 347,000 others like him in the UK and better diagnosis will probably reveal thousands more.

"Autistic children and adults are socially excluded at the moment and there needs to be a proper debate on inclusion for this group at every level of society. I believe an awareness year is the only way this can be done."

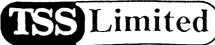


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From the Parliamentary Under Secretary of State Lord Hunt of Kings Heath



Richmond House 79 Whitehall London SW1A 2NS

Tel: 020 7210 3000

Q 1485/2000/2001

**OUSE OF LORDS** 

ARLIAMENTARY QUESTION FOR WRITTEN ANSWER

15/3/01

he Baroness Uddin asked Her Majesty's Government:

fow they intend to support the autistic community in the United Kingdom. (HL1115)

The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):

t is the responsibility of local statutory bodies to determine the provision of services to autistic reople based on their knowledge of local needs and priorities.

The Department of Health has issued guidance to encourage the development, at a local level, of a ange of well co-ordinated health and social services for people with learning disabilities, many of whom also have autism and their carers. Our strategy for services for people with a learning disability will be published as a White Paper in the next few weeks. Our increased investment in health, aducation and personal social services in England over the next three years will benefit people with autism as well as everyone else who needs them. Services for people with autism in other parts of the United Kingdom are a matter for devolved administrations.

From the Parliamentary Under Secretary of State Lord Hunt of Kings Heath



Richmond House 79 Whitehall London SW1A 2NS

Tel: 020 7210 3000

1 1528/2000/2001

**DUSE OF LORDS** 

**ARLIAMENTARY QUESTION FOR WRITTEN ANSWER** 

15/3/01

ie Baroness Uddin asked Her Majesty's Government:

w they intend to ensure local education authorities and National Health Service Trusts fund basic aucational services and specialist speech therapy for all autistic children. (HL1131)

ne Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):

ir increased investment in health, education and personal social services in England over the next ree years will benefit people with autism as well as everyone else who needs them. We have monstrated our commitment to improving the recruitment and retention of the Allied Health ofessions, including speech and language therapists, in 'Meeting the Challenge: A Strategy for the lied Health Professions' which I had the pleasure of launching on 25th November 2000.

nding is not made available for specific categories of special educational need. Rather, funding is located and distributed via Local Education Authorities (LEAs), who have a duty to provide propriately for all children in their area. This includes the duty to identify children's individual secial educational needs and to deliver the most appropriate provision to meet those needs.

nder the Standards Fund for 2001-2, the Department for Education and Employment is supporting penditure of £82 million on special educational needs. We envisage that local education authorities all spend £10 million of this on enhancing speech and language therapy provision in conjunction with the NHS and the voluntary sector. The grant is also available for training staff on special funcational needs issues.



At the individual pupil level we are also working to promote better and more consistent practice, owards all pupils with special educational needs. In particular the revised SEN Code of Practice should promote more consistent practice by schools and LEAs. Whilst individual pupils with SEN will arry in their needs it is important that schools and others adopt a consistent and rigorous approach identifying and providing for these needs.

Murall



### 2002 is Autism Awareness Year

The Disabilities Trust working in partnership with BIBIC the British Institute for Brain Injured Children,
and all other organisations who support those with autism,
will be facilitating a series of events that will run throughout
the year to help with the general understanding and
awareness of the needs of people with autism.

Jutism 2002

BIBIC



If you would like details of these events, or information on how you can be involved please register your interest with us now by telephoning either The Disabilities Trust on 01444 239723 or BIBIC on 01278 684060, alternatively you can register at www.autism-awareness.org.uk

# 2002 is Autism Awareness Year

# BIBIC - the British Institute for Brain Injured Children,

working in partnership with

### The Disabilities Trust

other organisations who also help those with autism, will be itating a series of events that will run throughout the year to p with the general understanding and awareness of autism.

ou would like details of these events, or information on how an be involved please fill out the attached form and return it

sIBIC, Knowle Hall, Bridgwater, Somerset, TA7 8PJ. or Tel: 01278 684060. Fax: 01278 685573 Email: info@bibic.org.uk Website: www.bibic.org.uk

Registered Charity No. 1057635

interested in autism and would like to be informed about forthcoming events.	
organisation would like to be contacted with a view to being involved during the year.	
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# 2002 is Autism Awareness Year

Autism Awareness Year was an idea shared by Ivan and Charika Corea, parents of a 5 year old Asian boy who is within the autism spectrum disorder.

A major conference

### **AUTISM 2002**

will be held at



### On Thursday 14th February 2002

Events connected with raising awareness about the condition will be held across the UK. 2002 Autism Awareness Year will be launched by the British Institute for Brain Injured Children, The Disabilities Trust, Allergy Induced Autism – ratified by the National Autistic Society, PEACH and a host of autism related organisations. 153 members of parliament of all parties signed early day motion 103 in the House of Commons in the Palace of Westminster backing the proposals. It remains to this day the most successful EDM connected with Autism.

For further particulars please contact -

Julic Spencer-Cingoz.
Chief Executive,
British Institute for Brain Injured Children
Knowle Hall
Bridgwater
Somerset TA7 8PJ.

Telephone: 01278 684060
Fax: 01278 685573
E-Mail: info@biic.org.uk
Website: www.bibic.org.uk
Registered Charity No. 1057635





## **AUTISM SUNDAY**

### 6<sup>th</sup> January 2002

The first Sunday of  $2002 - 6^{th}$  January has been designated AUTISM SUNDAY to remember the 450,000 autistic community in the UK. Churches of all denominations will be remembering autistic children and adults in prayer.

2002 has been declared as Autism Awareness Year.

It was an idea shared by *Ivan and Charika Corea*, parents of a 5-year-old Asian boy, Charin who is within the autism spectrum disorder. *The British Institute for Brain Injured Children* has declared 2002 as Autism Awareness Year — they will be organising Autism 2002 — a major conference on the causes of autism in January 2002. Events will be held throughout the year organised by many organisations.

### On Autism Sunday

- Please pray for the 450,000 strong autistic community in the UK pray for the families as well as children and adults they need a touch from the Lord.
- Pray for the Prime Minister, the Secretary of State for Education and the Secretary of State for Health Pray that God will guide them as they assess the needs of the autistic community. Pray for the research going on regarding autism and MMR.
- Pray for policy makers, local education authorities and NHS Trusts who are involved in the lives of all autistic people. Pray for the teachers and the speech therapists.
- Pray for autists who are lonely or sick. Pray for the elderly, the shut-in.
- Pray that people will have a better understanding of the condition, pray for all those involved in raising awareness of autism in our country.

If you would like to receive an information pack from the British Institute for Brain Injured Children – please contact BIBIC, Knowle Hall, Bridgwater, Somerset TA7 8PJ. Telephone – 01278 684060, Fax – 01278 685573, e-mail – julie.sc@bibic.org.uk. BIBIC is a registered charity No 1057635. Organisations wishing to raise funds for Autism 2002 or make donations are kindly requested to contact BIBIC.



### **EDM 103**

### **AUTISM AWARENESS**

13.12.00

152 signatures

AUTISM AWARENESS
Mr Piara S Khabra
Ms Diane Abbott
Mr Tony Banks
Mr A J Beith
Mr Roger Berry
Mr Tom Brake
Mr Paul Burstow
Mr Ronnie Campbell
Mr Michael Clapham
Mr Michael Connarty
Tom Cox
Valerie Davey
Mrs Janet Dean
Mr David Drew
Mr Jeff Ennis
Mr Ronnie Fearn
Mr Don Foster
Mr Mike Gapes
Dr Ian Gibson
Mrs Llin Golding
Mr Mike Hancock
Mr Ivan Henderson
Mr Lindsay Hoyle
Mr leuan Wyn Jones
Mr Martyn Jones
Mr Fraser Kemp
Mr David Lammy
Mr Terry Lewis
Mr Elfyn Llwyd
Judy Mallaber
Chris McCafferty
Mr John McFall
Mr Tony McWalter
Mrs Ray Michie
Laura Moffatt
Dr Doug Naysmith
Mr Martin O'Neill Mr Peter L Pike
Mr Bill Rammell
Mrs Marion Roe
Mr Phil Sawford
Mr Barry Sheerman Mr Dennis Skinner
Mr Careth Thomas (Clyvyd West
Mr Gareth Thomas (Clwyd West
Dr Jenny Tonge Dr Desmond Turner
Mr Paul Tyler

Mr Paul Tyler Joan Walley

Mrs Betty Williams Mr Mike Wood Derek Wyatt

Mr David Amess	John Austin
Mr Harry Barnes	Mr Roy Beggs
Mr Hilary Benn	Mr Gerald Bermingham
Mr Harold Best	Mrs Liz Blackman
Dr Peter Brand	Mr Russell Brown
Dr Vincent Cable	Mr Dale Campbell-Savours
Mr Martin Caton	Mr David Chaytor
Mr Harry Cohen	Mr Tony Colman
	Mr Brian Cotter
Mr Jeremy Corbyn	Mr Lawrence Cunliffe
Mrs Ann Cryer Mr Denzil Davies	Mr Terry Davis
Mr Andrew Dismore	Mr Jim Dobbin
Mrs Gwyneth Dunwoody	Mrs Margaret Ewing
Mr Bill Etherington Mrs Lorna Fitzsimons	Barbara Follett
	Mr George Galloway
Maria Fyfe	Mr Neil Gerrard
Mr Andrew George	Dr Norman A Godman
Sandra Gidley	Mr Win Griffiths
Mr Donald Gorrie	Mr Nick Harvey
Dr Evan Harris	Mr Stephen Hesford
Mr Stephen Hepburn	Glenda Jackson
Dr Brian Iddon	Lynne Jones
Ms Jenny Jones	Mr Alan Keen
Mr Nigel Jones	Dr Ashok Kumar
Ms Oona King	Dr Julian Lewis
Mrs Jackie Lawrence	Mr Ken Livingstone
Mr Martin Linton	Mr Andrew Love
Mr Tim Loughton	Mr John McAllion
Mr Paul Marsden	Mr John McDonnell
Mr Robert McCartney	Mr Kevin McNamara
Mr Eddie McGrady	Mr Bill Michie
Mr Alan Meale Mr Andrew Miller	Mr Austin Mitchell
	Ms Julie Morgan
Mr Alasdair Morgan	Mr Edward O'Hara
Mr Bill O'Brien Mr Bill Olner	Ms Linda Perham
	Mr Gwyn Prosser
Sir Raymond Powell	Mr Peter Robinson
Mr Syd Rapson Mr Chris Ruane	Mr David Ruffley
	Mr Jonathan R Shaw
Mr Alan Simpson	Mr Marsha Singh
Mr Alan Simpson Mr Llew Smith	Mr Peter Snape
Mr Andrew Stunell	Sir Teddy Taylor
) Mr Simon Thomas	Mr Mark Todd
Mr Jon Trickett	Mr Dennis Turner
Mr Neil Turner	Mr Stephen Twigg
Mr Bill Tynan	Dr Rudi Vis
Mr Robert N Wareing	Mr Dafydd Wigley
Mr Phil Willis	Mr David Winnick
Mr Tony Worthington	Tony Wright
,	. <del>.</del>

That this House backs the call of Ivan Corea to declare 2002 as Autism Awareness Year, aimed at raising the profile and the plight of autistic children across the UK; and urges local education authorities and NHS trusts to do more for autistic children, including autists from minority ethnic communities, to review and assess their educational services and specialist speech therapy services and change policies where discrimination has taken place

# Autism

Autism Awareness Campaign

256 Buckhurst Way **Buckhurst Hill** 

Essex IG9 6JG. Telephone & Fax: 020 8502 9747

Mobile: 07751032212

(Ivan Gra)

Autism becomes an Election Issue - voters will quiz the political parties about their commitment to autists.

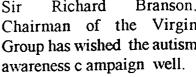


**NICK HORNBY FULLY SUPPORTS** THE CAMPAIGN

Celebrated author Nick Hornby has pledged his whole hearted support for the declaration of 2002 as Autism Awareness Year.

SIR RICHARD **BRANSON** WISHES CAMPAIGN WELL

Branson, Sir Richard Chairman of the Virgin Group has wished the autism





**CAMPAIGN** 

Tarrant wished the campaign lots of luck.He is mention it on poised 10 Capital Radio.

Britain is all set for a General Election in April or May this year, Politicians of all parties will now have to take the whole subject of autism very seriously indeed. Autism has now become an election issue. Voters will quiz Tony Blair, William Hague and Charles Kennedy about their plans to support the estimated 450,000 autists in the United Kingdom. Parents, charities, organisations are lobbying the government and urging the politicial parties to show they care for the autistic community by supporting the declaration of 2002 as 'Autism Awareness Year.' Voters want answers to the following questions:

- What plans do the political parties have to support autistic children and adults?
- Will they back the call to declare 2002 as Autism Awareness Year in order to raise awareness about the condition and focus attention onto the causes of autism.
- Will the parties pledge funding to the National Autistic Society to launch Autism Awareness Year?
- Will they organise Autism 2002 a conference on autism -which will also look at the MMR vaccination - alongside the National Autistic Society?
- How will they protect autists from the minority ethnic communities from discriminatory practices conducted by LEAs and NHS Trusts.
- What plans do they have to address the dire shortage of specialist teachers and specialist speech therapists trained in dealing with autistic children and adults.
- Will the political parties give an undertaking to tighten the SEN bill and make LEAs and NHS Trusts comply by supporting autistic children and adults with basic educational services and specialist speech therapy.
- Will the political parties pledge to launch a massive advertising campaign aimed at recruiting graduates as specialist teachers and speech therapists.
- Will they improve data collection of all autists and fund advocacy services?

The time for action is now. In 5 years time there will be a massive increase in numbers - the political parties will need to convince voters that they care for the autistic community.

independent Radio News sent a report about the campaign to 250 radio stations across the UK. Premier Radio and Choice FM had the campaign on the breakfast show and news bulletins on the hour. Public Sector Supplement had a lead article on the campaign fitled 'An Autistic Challenge. '98 Members of Parliament signed EDM 103 - an early duy motion backing the autism awareness campaign.

### 02 Autism vareness Year impaign Newsletter

C LAUNCHES AUTISM
VARENESS YEAR
RONESS UDDIN FOCUS
TENTION ONTO AUTISM
ITISM MARCH
REVENT

ring 2001 Imber 4

### 50 MPs BACK AUTISM AWARENESS YEAR

mbers of parliament - of all rties have now backed a parliament (EDM 3) supporting the claration of 2002 as Autism vareness Year. There is ong backbench support from Labour Party. MPs are ling on the government to pport this idea and several Ps are now writing to the ame Minister.

racting a great deal of oport in the House of Lords are Labour, beral, Conservative and ross-Bench peers are calling the government to support c idea of 2002 as Autism wareness Year.

ARE FOR THE FAMILY, OMMISSION FOR RACIAL QUALITY. CHILDREN ITH CANCER, ETHNIC INORITY OUNDATION, THE ORDOFF ROBBINS NTRE. BIBIC ARE MONG THE GROWING OF ' 'MBER RGANISATIONS PORTING THIS KEY MPAIGN. acre are 450,000 autists in

c UK and this number is set

rise in 5 years time.

2002 Autism
Awareness
Year Campaign

### BIBIC DECLARES 2002 AS AUTISM AWARENESS YEAR

AUTISM 2002 a key conference will be held next year in London.

The highly influential children's charity The British Institute for Brain Injured Children (BIBIC) based in Somerset are to declare 2002 as Autism Awareness Year. BIBIC will also organise a key conference Autism 2002 in London.

Also on the cards is an event in the House of Commons in the Palace of Westminster. A Calendar of Events for 2002 is being **BIBIC** compiled by individuals and organisations planning any events autism connected with are asked to awareness contact the British Institute for Brain Injured Children. BIBIC are to conrtact the National Autistic Society to request them to be partners in this venture.

Meanwhile the Scottish campaigner Bill Welsh is **OPEN** organising the YOUR EYES TO AUTISM' March in Edinburgh on Saturday 28th April 2001 to raise awareness of autism. are stewards Volunteer urgently required - for further details they should contact Bill Welsh on 0141 638 2859. The Action Against Autism are marching in an make the effort to government open their eyes to



the causes of autism and fully fund education and specialist speech therapy together with research into treatments.

Allergy Induced Autism (AiA) are also organising an event in London.

The highly respected Labour Peer, Baroness Pola Uddin focused attention onto autism by asking a series of questions in the House of Lords.

Lord Hunt says no
to funding conference on
causes of autismgovernment appears to
be out of touch with the
needs of the autistic
community in the UK

Under Secretary of State for Healthat the DOH Lord Hunt of King's Heath has stated it would not be approrpriate for the government to fund a conference on autism - this from a government who spent £700 MLLION of taxpayers money on the Millennium Dome, £234 million on Portcullis House, £140,000 for fig trees for Portcullis House. The government appears to be out of touch with the autistic community said one member of the media. Autism is now an election issue and voters are asking politicians do you really CARE for autists across the UK or are they mere hollow words.Oona King and other MPs are supporting an idea for a conference.

# BIBIC TO LAUNCH 2002 AS AUTISMAWARENESS YEAR

- The British Institute for Brain Injured Children will declare 2002 as Autism Awareness Year. The Chief Executive at BIBIC will also be writing to the Chief Executive of the National Autistic Society for joint participation.
- They are in the process of organising AUTISM 2002, a major conference on Autism scheduled to be held at the King's Fund in London in January 2002
- Also on the cards is an event in the House of Commons in the Palace of Westminster
- BIBIC are compiling a CALENDAR OF EVENTS for 2002 Individuals and organisations planning events connected with autism in 2002 are kindly requested to contact the Chief Executive of BIBIC
- People wishing to fund raise for AUTISM 2002 please also contact BIBIC. Companies and organisations wishing to support the key conference could also write to Julie Spencer-Cingoz, Chief Executive at BIBIC.



Bridgwater Somerset TA7 BPJ

Phone: 01278 684060 Fax: 01278 685573 Email: julie.sc@bibic.org

Julie Spencer Cingoz

Chief Executive Officer

Registered Charity No 1057635











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Thursday, January 18, 2001

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Campaign is 'needed to ensure therapy treatment is available to all children'

# **CRUSADING** ASKS BLAIR 'C



GETTING next year officially declared as Autism Awareness Year is the aim of the father of an autistic boy.

Ivan Corea, 43-year-old who lives in Buckhurst Way, Buckhurst Hill, has contacted

people including Prime Minister Tony Blair, Education Secretary David Blunkett, and the all-party parliamentary group on autism chairman Dr Stephen Ladyman MP with his idea.

Mr Corea hopes it will be promoted through events such as a conference on autism and

a national fundraising campaign for autistic charities. There needs, he feels, to be a national campaign to attract university graduates to work with children with special educational needs. He also hopes that during the Autism Awareness Year, if it goes ahead, local education authorities and NHS trusts will look at autism and come up with strategies to deal with an increase in autistic people. There are some 347,000 autistic children in the UK and in five years' time Mr Corea feels this number will rise dramatically due to better diagnosis.

Mr Corea explained that he first came up with the idea two years ago when he found out that healthcare professionals and teachers did not know much about autism and could not help his son Charin, aged four, who suffers from autism spectrum disorder and communication disorder.

**E CAMPAIGNER:** Ivan Corea

The healthcare worker said his son, who is about to transfer from Herewood School in Loughton to Buckhurst Hill Primary School in Buckhurst Hill, had not until now been able to get speech therapy, and the only

help he did get was music therapy. "When it comes to autistic children from minority ethnic communities, they are at the bottom of the pile. There is no ethnic monitoring, no advocacy service, no specialised speech

therapy, no language support, the dissemination of information in minority languages is non-existent," said Mr Corea, who comes from Sri Lanka. "Many ethnic families are not aware of their rights or are fully aware of the inclusion policy. LEAs and NHS health trusts need to

take a long hard look at their policies to see if institutional racism plays any part in it. The amendment to the Race Relations Act of 1976 will make it unlawful for LEAs and NHS trusts to discriminate against autistic

children from the minority ethnic community." He pointed out that some speech and language therapists are opting to do private work for a fee of up to £75 an hour instead of working for NHS trusts and said this was no good for people who could not

The government needs to find ways of helping pare children on therapies such as the Lovaas Programme which costs up to £30,000 a year, and issue guidelines on the drug secretin.

So far 66 MPs have signed an early day motion supporting Mr

Corea's idea and Mr Corea has had a letter from the Prime Minister's assistant which pointed out what the government and other organisations are doing about autism.

It mentioned the £344,000 being spent on finding the causes of autism, projects aimed at improving diagnosis and the five-year Quality Protects programme to transform children's services and

improve information available to parents.

Mr Corea would like anyone who wishes to support his initiative to write to the Prime Minister at 10 Downing Street, Whitehall, London, SWIA 2AA.

WIN our tickets to the movies! - see page 11

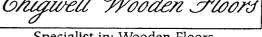


An icy case for our legal eagle RALPH **CAMP** 

– see page 13

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What your stars have in store for **YOU** - page 21

# TLING DAD WINS AUTISM CAMPA



By CLARE DEADMAN

THREE years of campaigning - with the help of The Herald - has paid off for Ivan and Charika Corea, the parents of an autistic

They have achieved their dream of getting next year declared as national Autism Awareness Year.

Mr Corea, 44, of Buckhurst Hill, learnt this month that the British Institute for Brain Injured Children (BIBIC) and the Disabilities Trust have decided to go ahead with his plan.

The National Autistic Society has ratified the year and more than 30 organisations have joined Autism 2002, which has been backed by 153 MPs. Mr Corea, whose five-year-old son Charin has an autism

spectrum disorder, said: "We are absolutely delighted that so many charities have come forward as partners of Autism 2002 - Autism Awareness Year. "We hope that it will raise awareness of the condition and

focus attention onto the needs of these children. A postcode lottery still exists when it comes to accessing education, health and specialist speech therapy for autistic children." To get next year declared as Autism year Mr Corea con-

CAMPAIGNER: success for Ivan Corea

tacted people including the prime minister, Tony Blair, and education secretary David Blunkett with his idea which should be promoted through conferences.

Another of his ideas, Autism Sunday, has also been taken up and on January 6 places of worship are to say prayers for the 450,000 people suffering from autism, and for the government to do what is right for autists across the country.

Mr Corea first came up with the idea of getting 2002 declared as Autism Awareness Year when he found out that healthcare professionals and teachers did not know much about autism and could not help Charin.

He battled to get the Buckhurst Hill Primary School pupil an hour's speech therapy a week and is still fighting for

He put his case to The Herald and we put the story on our front page, of which Mr Corea said he sent copies to lots of people.

He said that autistic children from ethnic minority communities have no language support, no advocacy service, and many of their families are not fully aware of the inclusion policy.

Mrs Corea said: "We see Charin as a

special gift from God - he has a sense of humour and brings us so much joy. People must not see these children in negative light, they are wonderful human beings - they may be different but society and the community needs to look at these children as valuable members of the commu-

To help get the best out of next year BIBIC want autism support groups to get in touch with them as it has funding for small organisations to run awareness events. Groups should call 01278 684060.

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# Winning battle for Autism Awareness Year

WE WANT to thank the hundreds of people who have written to the Prime Minister, Tony Blair, asking him to back the call to declare 2002 as Autism Awareness Year and allocate funding of £750,000. This will help autism organisations such as the National Autistic Society in London and the British Institute for Brain Injured Children in Somerset to organise events for Autism 2002 including a conference looking at the causes of autism especially the MMR controversy.

We also thank The Herald for its support.

So many people have been in touch with us stating that autism is now an election issue. We have even received letters stating that if the government has spent millions of taxpayers money on the Millennium Dome and other buildings, then a £750,000 grant to raise awareness on autism is peanuts.

There are 450,000 autists in the UK and this number is set to rise dramatically in five years' time. Education and health professionals are not prepared for such a huge increase. There needs to be on-going training for teachers

in Essex, where there are so many autistic children across the county. It is all well and good to have an inclusion policy but schools must be adequately funded — the DfEE needs to set up and fund autism units in mainstream schools where there are autistic children; launch an immediate advertising campaign to recruit specialist teachers trained in dealing with autistic children; recruit specialist therapists — in Essex there is a crying need for them.

I think people are being far too complacent and too busy patting themselves on the back when autistic children are not being supported and given the education they deserve. It is a fundamental human right, not some special favour, for children with SEN. A postcode lottery to education, health and specialist speech therapy still exists across the UK. The government has assured us that millions of pounds will be allocated to support the autistic community, but in practice these monies are not reaching places like Essex.

Parents are struggling to overcome the under-investment in the area of special educational needs. As a result,

autistic children suffer. Voters have assured us they will first quiz the government to see whether they plan to practice what they preach and support the proposal for an Autism Awareness Year. One hundred and forty four Members of Parliament – of all parties – have backed a motion in the House of Commons supporting the declaration of 2002 as Autism Awareness Year.

Baroness Uddin has called for a debate on autism in the House of Lords. Lord Jack Ashley, Lord Dholakia, Lord Naseby, Sir Richard Branson, Nick Hornby and Chris Tarrant are among the thousands supporting the campaign. We are grateful to MPs Linda Perham and Bill Rammell who have lobbied hard on behalf of their constituents for a better deal for autists. Two wonderful Members of Parliament who have cared for autistic children and adults in this part of the UK. – Iwan and Charika Corea, Buckhurst Hill.

The Editor welcomes readers' views on any subject. Letters may be shortened for legal or other reasons. Please write to: The Editor, The Herald, Recorder House, 539 High Road, Itlord IG1: 1UD. Fax: 020 8478 8584, email: herald-wnews@ser.co.uk

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# A dangerous power game

WE'VE got a welcome opportunity for consultation about the way the council makes decisions in future.

Harlow Council's aims of increasing openness, accountability and involving more people in decision-making are excellent. But the government's recent fourth option of an improved committee system seems potentially more democratic than cabinet and leader.

I support reservations about the two "mayor options":

- two much power for one person
- can't be removed for four years
- personality politics.

The council's preferred option is for a cabinet and leader. But research on early cabinet models

senior management, with access to and control over – information.

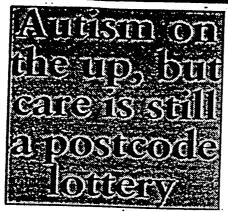
The sovereign role of the whole council is diminished.

The much-maligned committee structure had its strengths. Power was shared more widely and openly amongst councillors and staff. Public and press accessibility to meetings increased potential influence and accountability.

The council is the ultimate sovereign body, determining policy – for public record. It is not simply a debating chamber for competing party political resolutions.

Harlow's area committees could be strengthened. Executive powers over local budgets could involve more residents. They could also ful-





WE want Prime Minister Tony Blair to declare 2002 as Autism Awareness Year, and to allocate funding of £750,000 for its launch and for autism organisations such as the National Autistic Society in London to organise events like Autism 2002 – a conference looking at the causes of autism, including the MMR controversy.

Autism is now an election issue. The government has spent millions of pounds of taxpayers' money on the Millennium Dome, so a £750,000 grant to raise awareness on autism is peanuts.

ucational and health professionals are not prepared for an increase.

There are so many autistic children across Redbridge. It is good to have an inclusion policy, but schools must be adequately funded. DfEE needs to set up autism units in mainstream schools where there are autistic children, and to recruit specialist teachers and specialist therapists. In Redbridge there is a crying need for such professionals.

A good education is a fundamental human right, not some special favour for children with special educational needs. A postcode lottery to education, health and specialist speech therapy still exists.

On paper the government has put millions of pounds into supporting the autistic community, but in practice these monies are not reaching across the UK. As a result autistic children suffer.

Across the parties 140 MPs have backed a motion in the House of Commons in support of declaring 2002 as Autism Awareness Year.

We are grateful to Linda Perham (MP for Ilford North) and Bill Rammell (MP for Harlow) who have lobbied hard on behalf of their constituents for a better deal for autists. These two wonderful MPs have done their bit to care for autistic children and adults in this area.

IVAN and CHARIKA COREA Buckhurst Way Backharst Hill

# Private by

UR underground system - much used by local peo-Olk underground system - mann and provement, improvement, successful management, yet the mayor and his transport commissioner are still locked in an ongoing argument with the government over the proposed PPP (public private partnership).

Transport commissioner Bob Kiley has said: "It smells like privatisation. It walks like privatisation. It talks like privatisation."

Many people are highly dubious about this course of

action, having Tories' rail pri Moreover, in Frank Dobson: anti-privatisatic termined to pre

Londoners d Democrats have be raised by issa in public hands.

# lat runne

There are 450,000 autists in the tricle on the de-UK and this number is set to rise cision by councillors to dramatically in five years' time. Ed- make permanent the oneway traffic management scheme in Brian and Somerville Roads (Recorder, April 19).

The councillors of Chadwell Ward were bound to accept the recommendation from the chief highways officer.

If not, the scheme would have been

shown up for what it is -a total vpublic money.

What were these people thin! when they began playing King ( Traffic is like water, it will alwaits way into an area if unchecked.

The one-way scheme simply de work, and has forced other resiroads in the area to suffer the quences of a bad decision made b witted amateurs.

My concern over the above sch wrapped up with another issue: a t calming scheme in my road that cope with the displaced traffic fre

# Killing fields are preterab

THE effects of foot-1 and-mouth disease are dreadful, and its economic consequences spread far wider than the farming community.

But there's still a lot of hypocrisy around which is not helping to find solutions. Farmers claim to be upset at the killing of day-old lambs.

Yet these same farmers happily send them long distances to market, or even further overseas for slaughter, when they are just a few weeks older.

All farmed animals are bred for slaughter and for

no other reason - 900 million of them annually.

The dreadful irony is that a quick death on the farm because of foot-andmouth is almost certainly preferable to days of transportation, the brutality of livestock markets and the terror of the abat-

I think people have to k themselves what it is that upsets them. The slaughter of lambs is intolerable, but it won't stop when foot-and-mouth does.

Day-old bull calves will still be taken from

their mothers and pigs, sheep cattl poultry will still f: end in the slaughter.

If the slaughter nocent animals does upset you, change your diet an eating meat.

These disease demics are getting and more frequen such as BSE: coli, kill humans tox

Going veggie i just a moral step - i save your life.

SANYA PRES Pécl 1 Cla

been inundated with enquities S a patron of the Vegetarian Society A and having been vegetarian myself members of the public wantimes was

A YEAR ago the Friends of Valentines Mansion was

# An autistic challenge

man, is a man on a mission. He wants the Government to declare 2002 Autism Awareness Year. The campaign aims to raise awareness of the plight of all autistic children but specifically Black and Asian children. who suffer a double disadvantage

Ivan from Buckburst Hill in Essex old hov. Charin. He was born after a difficult labour and appeared to reach all development milestones until he was 18 months old. Their GP suspected that Charin had a Personing was two years later before a diagnosis of autism spectrum disorder was con-firmed. Since then the family has had an ongoing battle to get the appropriate support for their son. Charin is musically and mathematically gifted, attends an ordinary nursery school from which he will move on to the local primary school in September herapist so they pay £75 an



'When it comes to autistic children from minority ethnic communities, there is no ethnic monitoring, no advocacy service, no specialised speech therapy or language support'. Public Sector meets one father who is spearheading a campaign for a better deal.

PRAWING C. Stephen Willshire's American Dream

ground of frustration that the idea of an awareness year was born. Ivan explained: The campaign

started when my son was diagnoses with autism spectrum disorder and a then that healthcare professionals and teachers did not know much about autism. To this day my son has no specialised speech therapy It has been struggle to overcome the catalogue of discrimination, neglect, apathy and incompetence "

"My wife has had to give un her joh as a head-teacher to look after Charin.
The immediate effect was a drop in the family income. The bulk of care still falls on her. We have no social life as everything revolves around our son We are lucky that we have no other the family can cause friction. We've been lucky because we are committee

Recently Dr Stephen Ladyman MP, Group (APPG) on Autism in the the many families struggling to overcome this 'postcode lonery' healthcare and education for their

> Despite increasing awareness that autism crosses all ethnic groups, sup-port services take little account of the Day Motion which has attracted cultural background of the child. The stigma associated with autism is as powerful as ever, with the result that vill need to sign the motion some parents vehemently deny that they have an autistic child. Without adequate information and support Black and Asian parents, look for causes within the family. Mothers in particular often feel, or are made to something they have done, or not done. And while there is a growing body of literature on autism, ethnic diversity within autism remains unacknowledged. There is little recognitio of Black and Asian people's legitimate lain to have multiple identities

> > even begun to be addressed In 1987, 13-year-old Stephen architectural drawings. The Black autistic teenager was hailed a genius and did much to highlight the fact that

Either they are autistic or they are

Black, not both. And the fact that

Black and Asian children may be mur

ginalised and experience racism with-

chance of being allotted debating time.

Support has also come from the Commission for Racial Equality and

charities including the British Institute

for Brain Injured Children, the Nordoff-Robbins Centre for Music

Therapy, Children with Cancer and the

Sector Organisations

Council for Ethnic Minority Voluntary

Genius: At the age of 13, Stephen Wiltshire had books of his architectural drawings published too. Unfortunately the fascination to a policy change which added race to local authority's service provision

> Autism is a lifelong disability, which disrupts the development of social, and communication skills, isotheir family. First described in 1943 by American Leo Kanner, it is a complex condition, which affects four times as many boys as girls. Approximately 70 accompanying learning difficulties Autism is a range of conditions, which includes Asperger Syndrome (AS) Children with AS have the characteris-



Cores: Leading the campaign

tics of autism, but are of average of

many different forms but will includ an apparent indifference to others, the ple's feelings. Most autistic people have difficulty in acquiring, using and cation such as gestures and facia preference for routine and a preoccu like change and often appear conten



There are no accurate figures of the number of people with autism. At a recent APPG meeting, John Hutton, Minister of State for Health, gave a figure of 450,000 or approximately 56 pe known how many are Black or Asian because there is no ethnic monitoring

WEEK ENDING 2 FEBRUARY 2001

There is currently no cure fo autism, but early intervention with spenur can beln maximise a child's skills right kind of education and care promes is essential. They make a real each individual, whatever their level of disability, to achieve as great a degree of independence as possible

The exact causes of autism are no known although experts believe it has a physical rather than mental origin. Ir other words, autism is not a form of mental illness. Studies suggest tha autism can be caused by a variety o conditions affecting development of those parts of the brain that integrate language and information processed from the senses, and which can occur beture, during or after birth. These include, maternal rubella, lack of oxygen at birth and complications of child hand illnesses such as whooping cough as MMR, given to children to preven

Diagnosis is difficult because autism resembles other behaviour, learning and communication disorders. Many professionals only come across a few tise in recognising the signs Language and hearing can be a prob-lem in assessment. Some children initially thought to be deaf turn out to be non-responsive autistic, rather that have a hearing impairment

Parents are in a catch 22 situation They need an early diagnosis, as th will trigger support services. For instance, in order for the child to access specialised local authority ser vices he'll need to be statemented and this cannot happen without a confirmed diagnosis But diagnosis in very young children has its own prob-lems Often 'autistic-like' signs noticeable in under-two lend to disag pear as the child gets older

Nevertheless getting appropriate parents are able to find out what is available the better. As Ivan explained "Many teachers are unaware of strategies to deal with autism. In Essex when Charin joined his nursery school they did not know a great deal about his condition or had hought about strategies to deal with

MP Linda Perham, says the root cause of the problem in her constitueney is the fact that local services are administered through different sources education department, health authority and social services department

It also depends on the severity of





### MPs in support of the Autism **Campaign Early Day Motion**



will attend mainstream schools but will

because they have other physical prob

lems or go outside the borough if their

needs cannot be met within the bor-

ough and this is generally paid for by

Education Authorities are reluctant to

fund some 'new' treatments or pro-grammes that they believe are no better

than what they already offer Generally

through the appeal system which can

be very time consuming and also very

Often parents have to resort to the

courts to get the service they need. This is exactly what Angela White did

In 1998 she challenged her local authority Ealing in the High Courts

cational needs for her two autistic chil-

Su Thomas, chair of PACE (Parents

Autism Campaign for Education) commented. We know of hundreds of par

LEA. I believe that Local



will help them realise that investing i

intensive early intervention could actu-

Without early intervention there is

an additional lifetime cost to society

for people with autistic spectrum dis-

der calculated at as much as three mil

Mental Health Foundation with funding from the Shirley Foundation, the study found that the greatest costs, potentially £40,000 per year per per-son, were those of residential care for

dults with autism. Less than £13,000

of this is spent on special education for children, where early intervention may



ents who face active opposition from This research shows for the first thlic authorities when they try to instigate a programme of early inter-vention for their children. Many are time the true cost of autism and Asperger's syndrome, said Dr Jo forced to take out loans and suffer financial hardship," "It seems that local Borrill clinical research manager Mental Health Foundation. "It is a very strong argument for more energy and authorities are prepared to spend battles, rather than in investing in these children's futures. We hope this report need for such intensive services later

within society.

which will make it easier for people

supported employment oppo

To register your support for Autism Awareness Year 2002 please complete and return to Ivan Corea. 756 Buckburst Way, Buckburst Hill, Essex 1G9 6JG. TeVFax: 020 8502 9747 or email: I.Corea@kings. fund.org.uk

### Housing for Ke Workers Withi

Nottine Hill Home Ow Starter Home Initiative laur Housing. The pack explain NHHO can work togethe partner organisations to tac problem of recruiting and key staff in vital public serv London. Affordable housin central issue in both retain recruiting key workers. The .
Home initiative will provide of £250 million in public su over three years to help 10,000 key workers on moderate incomes with demand areas like London. I Housing Corporation an Environment and the Regio

### Councils housi melt down

Figures from the housing services have deter in the past year, possibly due lack of a full-scale housing torate. The annual survey of than 100 key performance tors covers council servic vided in the 12 months to 2000. Since then the gove has introduced its "best regime requiring councils to tor the competitiveness o services. The study shows c percent of council housing are completed within gover time limits, and the num housing lets with rent arre nore than 13 weeks has als percent to 4.6 percent. In only 68 percent of housing and council tax benefit cl are satisfied with their cour vices, while the figure is 78 ecross the country. The sion also reports deep dis tion from the public at the of police foot patrols - le one in five people survey happy at the number of " on the beat." Overall, loca cits' delivery of educati Improved.

### Exclusion threa poor pupils with uniform

Children from poor far afford the cost of unifo Cicizens' Advice Bureau h on the government to ord grants for low income fa-125 local education au financial help, it said. Only vided help at both prin secondary school level authorities restricted the cases to only once in career. Some schemes parents on income supcould demonstrate ex

Public Sand ASIAN TIMES & Caribbean Times

Public Sector · ASIAN TIMES & Carabi

# Research demanded Over rise in autism

By Nigel Hawkes Health Editor

GREATER efforts are needed to identify why autism in children is rising so rapidly, a specialist in the condition said yesterday as research showed that diagnoses have risen tenfold over the past decade.

Paul Shattock, director of the Autism Research Unit at the University of Sunderland, was presenting results of research at a conference at Durham University.

Similar increases have been found in other countries, but no common underlying factor has been identified. Many specialists supect autism first defined as a distinct condition in 1943 — has become a fashionable diagnosis for behaviours that once would have been dismissed or classified differently.

Autism is a disorder characterised by difficulties in social interaction and communication skills. It typically occurs in the first three years of life. and is four times more common in boys than in girls.

Mr Shattock said: "Our records give a strong indication of a very large increase in the incidence of autism over the last ten years."

Similar results have come from a study of records kept by British GPs, analysed by a US team from Boston University. They reported recently that these records showed a sevenfold increase in diagnoses of autism in children aged under 12 between 1988 and 1999.

Campaigners have argued nat there is a link between the apparent increase in autism and the introduction of the measles, mumps and rubella vaccination. Mr Shattock believed that MMR was one

possible cause of the increase, and called for more investigation. "MMR is certainly one of the elements and one would think it should be explored adequately, and we think it has not been," he said. "Nobody can say there is a definite link, but we say there is evidence. but not proof. Vaccines have been given all the publicity and they are in the frame, but we also think pesticides are

Mr Shaddock, a pharmacist who has researched autism for 20 years, said that changing dietary habits and food additives might be one element. He added that the brain was the body's most sensitive organ and could be susceptible to slight changes in diet. He added: "It is probably lots of things and they act in a cumulative way."

He agreed that better diagnosis was one reason why more children were being found to have the condition, but said that the higher numbers of younger children suggested a real increase.

The Boston team do not believe that the MMR vacination can explain the rise, which did not coincide with the vaccination's introduction in Britain. The increase could be due to increased awareness of the condition among parents and GPs, changing diagnostic criteria, or environmental factors not yet identified," the team reported in the British Medical Journal.

Mr Shaddock's call for more research was backed by Liam Fox, Shadow Health Secretary, who said: "We need to know whether the increased number of cases is due to better diagnosis, greater clinical suspicion or a genuine rise in the number of children afflicted with this condition."



Thousands of artists enter paintings for the Royal A

# Entrants exhi

By Dalya Alberge Arts Correspondent

ARTISTS must suffer for their art and not even repeated rejection from the Summer Exhibition could keep them away from the Royal Academy of Arts yesterday.

Defiant would-be entrants returned in force, undeterred by repeated exclusion from the world's largest open show. With Constable and Stanley Spencer among the former rejects, they will at least be in good company if the worst comes to the worst.

On the first day for submitting oil paintings. lines of bubble-wrapped packages of all shapes and sizes were delivered with the loving care of a

mother taking her child to nursery. Pictures showing real talent, mediocrity or worse were unwrapped and handed to RA staff. Owners looked on eagerly as their creations were taken away to be stacked with thousands of others.

Most of the artists were good-humoured, but some had such downcast expressions that it was as if they knew that the only walls on which their work would hang would be those at home.

Sheila Grady, 70, was hoping that it would be fifth time lucky after previous rejections. She came down from Coventry yesterday with a friend to deliver abstract paintings which she had tried to make as "modern" as possible to

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## IN THE INDEPENDENT TOMORROW

## Woman on the verge: Penelope Cruz talks about celebrity, Captain Corelli and Nic Cage

Twelve pages of film, music, arts and listings in the Friday Review

### SCIENCE

Foot-and-mouth: is vaccination the answer?

### THE KNACK

The expert's quide to solving life's problems

**EHEALTH** Dangers of pollution, pesticides and eating habits must be investigated to find cause of disorder, says leading academic

# Tenfold increase in cases of autism alarms doctors

BY LORNA DUCKWORTH Social Affairs Correspondent

A TENFOLD increase in cases of autism over the past decade prompted a leading academic to call yesterday for new research to establish the cause of the developmental disorder.

Paul Shattock appealed for urgent action to find out what was behind the huge increase in cases, which he blamed on environmental influences and

which range in severity from classical autism to a milder con- the research unit's database, dition known as Asperger's which was published yesterday. syndrome, are thought to affect 500,000 families in Britain.

Autism Research Unit at the or greater awareness about University of Sunderland, said the condition, which can result there was no proof, one way or another that the controversial MMR vaccine for measles, mumps and rubella was responsible for the increase. Re- of autism and diagnostic critesearch into MMR's possible ria have changed slightly," he role in causing autism had so said. "But even allowing for this, far been inadequate and a all over the world there seems study planned by the Medical Research Council would not settle the issue, he said.

for their child's autism, but the Government and nearly all doctors have declared the vaccination safe, warning that non-vaccination carries much greater risks for a child.

Dr Shattock's warning about the rise in autism followed



not just genetic predisposition. Shattock: 'Big increase' in Autistic spectrum disorders, autism across the world

He said such a steep rise was unlikely to be caused simply by Dr Shattock, director of the changes in diagnostic practice in severe language, behavioural and socialisation problems.

"Clearly there is increased to be a big increase in incidence, and we have to look at all the things that have hap-Many parents blame MMR pened in the meantime to see

what is likely to be relevant. "There are many possible must be environmental factors involved and there are many possibilities, all of which need to be explored. Our theories inan analysis of 6,000 people on clude everything that has

changed - pesticides, infectious disease patterns, vaccinations, plastics in bottles, the fact that we are eating different foods to what we were eating before, different bacteria in our intestines, heavy metals, pollution, anything really."

Other possible triggers that have been cited include illness during pregnancy, childhood illness and food intolerances.

Dr Shattock said a link with MMR had not been proved, but some parents reported a drastic behavioural regression in their children after receiving the MMR vaccine. "There is a huge amount of anecdotal evidence from thousands of parents in the UK and tens of thousands of parents around the world who all believe that this is a factor. It should be explored adequately," he said.

A recent study in California reported a 273 per cent inawareness and understanding crease in cases of autism over 10 years and British research. published earlier this year, showed a sevenfold increase between 1988 and 1999 in boys aged two to five.

Charities such as the National Autistic Society also reported what appears to be a big rise in the prevalence of autism, particularly the severe rather reasons. Clearly, if there is an than the more subtle forms, and they see one child a week." increase in numbers there suggested that increased diagnosis did not explain the increase. Calls to the society's fordshire, was diagnosed as two years from 800 a month to ways, Joe appears to be a fair-play with trains on long straight more than 2,500. Elleen Hop- ly typical nine-year-old. He tracks, and eat a meal all at the but getting anyone to believe it

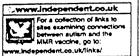
kins, its director of development and outreach, added: "Teachers working in the field have said they used to deal with one case a term, but now Joe Phillips, the son of Terri and Gary Phillips, from Hert-

videos and is fascinated by trains, but he suffers from a severe form of autism that makes his behaviour unpredictable. His language is limited, and he can be very rigid about how he spends his time. He likes to do lots of things at once. He will helpline have tripled in the past autistic four years ago. In some watch a video, listen to a CD,

loves music, is obsessed with same time. But if his mother turns on the vacuum cleaner, the noise will upset him.

Joe, who goes to a special boarding school, does not like trums'. To be honest, I was reunfamiliar places and even a trip to the supermarket can result in a screaming fit. But he has remarkable powers of memory. Mrs Phillips said: "You know something is wrong,

is impossible. People think it is just a phase. Doctors say it is the 'terrible twos'; they tell you 'toddlers have temper tanlieved when he was diagnosed."



### Army of matrons back on the wards next April

BY LORNA DUCKWORTH

AN ARMY of 2,000 matrons is to be put to work in Britain's hospital wards after an absence of 30 years, Alan Milburn, the Secretary of State for Health. said yesterday. The first 500 modern matrons will be in post by next April and take overall charge of three to four wards covering specialties such as cancer, paediatrics or surgery.

They will have control over budgets, catering and cleaning, take responsibility for driving up standards, preventing hospital infections and liaison with patients and their relatives.

The matrons, who will all be in place by 2004 and will earn up to E31,000 a year, should be easily identifiable by distinctive uniforms and name badges, Mr Milburn said. They will be in charge of cleanliness and food on the wards and have the power to withhold payments from catering firms that do not perform well.

Matrons will also be in charge of ensuring frail and vulnerable elderly patients are treated with respect and able to eat their meals, in response to claims that food is left out of reach at the bottom of beds.

Mr Milburn said: "Patients want to know who to turn to. They need to know who's in charge. Matrons on the wards will have the authority to put things right for patients. Matron will make sure the wards are clean, the food is good, the care is there."

Christine Hancock, general secretary of the Royal College of Nursing, said: "Patients have been crying out for someone they know to be in charge on hospital wards. Giving modern matrons enough staff, the right



Joe Phillips, 9, who is severely autistic, and his mother, Terri. He will need care all his life

King's Fund

