

Feature

Building grass roots support

By Wendy Kiefel

An important part of advocacy is building community understanding and support for people with autism. It's important because;

- It educates people about the difficulties people with autism face in their daily lives.
- It broadens the dialogue and makes government accountable to the whole community not just those directly affected
- Politicians respond to issues if they think those issues have grass roots support.

How to build grass roots support

It can be done in a variety of ways. Some ways that have worked is to offer our services as guest speakers to branch meetings of major political parties, churches and other community groups. We have also approached churches via email and through personal contacts to ask for the prayerful support of the congregation. Big issues that started out small such as Asylum Seekers and Aboriginal Rights have used these methods.

How to start

Personal contacts and introductions are one of the easiest ways to get started. If you have contacts, use them. Otherwise some suggestions are;

Political parties

The major parties have a secretariat in each state which are listed on their web sites. Contact them by phone and follow up in writing. Ask to be put in touch with the convenor of the relevant policy committee. eg education, health, disability. When you speak at their meeting, ask the policy committee members for a referral back to their branches.

If you already have contacts, consider which branches would be most effective to speak at. For example does the branch fall within the electorate of a government minister, parliamentary secretary or shadow. Are any key ministerial advisers involved with the branch ? Do your homework, read the MP's biography on the net and Hansard for any thing they have said in parliament on a related subject.

Churches

The major denominations have web sites with email contacts for individual priests or ministers. This makes it easy to contact hundreds of churches quickly and

cheaply. It is a good idea to personally address your email message to the priest or minister.

You can ask for a speaking engagement (I have not personally done this) or ask for the congregation to include you, your issue etc in their prayers. Some churches operate e-mail prayer chains and hold regular prayer meetings and vigils. If you are lucky the church might respond to your request with an offer of lobbying support.

What to say

If the thought of public speaking terrifies you find a friend and share the speaking.. You don't have to give a long and formal talk, plan to speak for about 5 minutes and then invite people to ask questions. Your experience is out of the ordinary so your audience will be very interested and ask lots of questions. If you feel nervous because you are not an experienced speaker remember that it is easiest to talk confidently about subjects you know really well and feel passionate about. Use notes to help you to remember everything you want to say. People like to hear about other people and their experiences so tell your story from your own perspective.

If you are talking about an autistic son/daughter/relative/friend take

along some photos so that your audience can see the person you are talking about. Use his or her name often to keep the autistic person firmly in the picture.

Use some statistics and facts – the A4 web page is a good source.

Say what you would like government (local, state or federal) and the community to do. Explain why it is of long term benefit to the whole community that autistic people are given the help they need.

Depending on your audience it may or may not be appropriate to directly ask for help. You should however be prepared for offers of assistance. Be clear on what you want individuals or an organisation to do. Some suggestions are in the next paragraph.

How community groups can help us to advocate for autism

Political Parties

- Referral to a ministerial staffer or minister
- Referral to a policy committee
- Contacts and referrals to other branches of the organisation if you want to line up another talk
- Write letters to MP’s and ministers you could have a form letter ready for them to send their MP (have the name, address, email of relevant MP’s and ministers as well as they key points that should be made)
- A resolution to be submitted at their next state meeting or policy meeting

Community Groups

- Fund raising or sponsorship
- Letter writing to papers and MP’s

- Signing petitions

Churches

- Letter writing to papers and MP’s
- Signing petitions
- Inclusion of autism in their prayer meetings
- Understanding and accommodation of people with autism at church, denominational schools, church run play groups, Sunday schools and youth groups

Even if you do not get any offers of help, remember it’s never a waste of time to speak about autism, you are helping to increase community understanding and compassion. From little things, big things grow.

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From the Convenor

Dear A4 member

With the start of a new calendar year I find myself reviewing what A4 has achieved and what need to achieve.

Our Treasurer, Jean Hawkins, has some other things to do in her life: as she will not be available to perform this function she has stepped down. Please join with me in thanking her for her effort and support, and in wishing her well in her travels.

Many of our members are just beginning a new school year. Generally this is a period of considerable challenge. It may help to remember that every challenge provides an enormous opportunity for a significantly better outcome. At this time, I remind myself to stay open to ideas and suggestions, to be flexible and to focus on goals and ensuring outcomes (rather than insisting on doing things my particular way).

Most people are more committed to implementing their own ideas rather than someone else's. If you can help teachers, support workers and others "discover for themselves" what it is you want to happen, they are more likely to succeed. If possible, lead them to a solution but let them "own" the idea so they commit to it.

Please share your positive experiences with other A4 members. Write to our editors with the best solutions to the challenges you encounter. Challenges vary for different people, so solutions vary as well. Let us know what works for you.

Some A4 members are meeting soon in Beechworth, Victoria. We definitely want input from members who cannot be there. Please send us your priorities for A4 and how you suggest we achieve our goals. I am very conscious that many members cannot be there so I want to ensure you can contribute.

This is an election year. We have an opportunity to get our ordinary members, the ones you vote for personally, to commit to trying to help people with ASD. I would like to urge A4 members to contact their current political representatives at the federal level and let them know you need assistance and how they can help.

Making sure you know your electorate. If you don't know, call the electoral office and ask. Look your member up on the parliamentary website (www.aph.gov.au). It doesn't matter which party they belong to, put the contact details (name, address, telephone and email) in your address book or on your fridge. We'll provide some draft letters and suggestions that you can send to your member if they are issues you feel you can support.

Of course, we encourage you to raise your own issues with your elected representatives. We encourage local support groups to raise local issues as well. You can also write to the senators for your state ... they are also your elected representatives in the political system. Ask them to represent you and others in your position.

Regards
Bob Buckley

Editorial

Job Vacancies

We are still looking for members to be our state correspondents from **SA, WA, QLD, NSW and NT** for the A4 Update. This would involve a monthly round-up state related ASD issues. This is a great way to become more involved in A4 and advocacy in general. If you are interested please contact us at

edit@A4.org.au for further information or simply forward your information to the above address.

Note

The next issue will be out at the end of March. All reader's contributions and inclusions for the March issue must be sent to edit@a4.org.au by March 16 for

the next Update. All contributions are welcome.

DISCLAIMER

The information, articles, reviews, books and websites contained in this publication are presented in the spirit of keeping you informed and aware of developments in the field of autism spectrum disorder (ASD) and Asperger syndrome.

They are not intended as a substitute for obtaining an individualised evaluation of your child and the advice of qualified

health professionals trained in ASD.

The statements made by various authors regarding products or

services represent the views and opinions of those authors and do not constitute a recommendation or endorsement by the publisher.

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Letters to the Editor

Funding fury

Dear all at A4,

First let me say how really impressed I am with the web site - not only is it full of really useful and relevant info but it has been a pleasure to navigate round the site. Thank you to all the very hard working people responsible for this.

My query relates to a specific client of mine (- I should mention I'm a psychologist and in this instance, I'm speaking as a private practitioner). My client and her family were recently informed

they had missed out on funding for an integration aid at her (small) independent school. Although she has been diagnosed with high-functioning Autism, her communication skills (semantics and pragmatics) are extremely poor (sound familiar to anyone?). Her parents, other therapists and myself feel strongly about "appealing" this decision (or at least kicking up a fuss). I'd be grateful to get any advice/support from either other parents or professionals who could at least start us off in the right direction. I don't know how to canvas this

support, except maybe via your newsletter (if that's appropriate?). Is it perhaps more appropriate to set up some sort of chatroom? Is there somewhere else we could turn?

Thanks so much for your time and energy.

Kind regards

Sonia Street

Editor's note: Should you have any information or wish to assist Sonia in any way, please forward to edit@a4.org.au.

Courier Mail Article

Dear a4:

Please find attached the recent article from the Brisbane Courier Mail.

Due to a lack of intensive early intervention services in QLD we have started a charity (AEIOU)

with the specific aim of developing such a program.

We would be very interested in any support you can provide from an advocacy viewpoint.

In an immediate basis I would be interested if a spokesperson from A4 would have any comments to make on the Courier Mail article

and in particular if they would be prepared to write a supportive letter to the editor of the paper.

Yours truly,
James Morton

Please see State Round-up Queensland (which is the Courier Mail article)

'Your Say'

Yes ... we still want your feedback. Tell us how we're doing, what you want more of, what you want less of, what's missing, etc. Email us at edit@A4.org.au with 'your say'.

National/State Roundup

National

Third term for National Disability Advisory Council announced

29/01/2004

The Minister for Family and Community Services, Senator Kay Patterson, today announced the appointment of nine new members for the third term of the National Disability Advisory Council.

The new members are Mr Nigel Webb (QLD); Ms Adele Gibson (QLD); Ms Deidre Croft (WA); Dr John Entwistle (SA); Dr Paul Collier (SA); Mr Byron Davis (NT); Ms Janice Slattery (VIC); Ms Ruth Jacka (NSW) and Ms Alison Lumby-Herridge (NSW). They will work with existing members Dr Lynette Davis (NSW), Ms Christine Kerr (WA), Ms Cheryl Shuttleworth (TAS) and Mr Ian Trehwella (ACT).

"I am pleased to advise that the Council will be chaired by Mr Ian Spicer AM for a further 12 months. Mr Joe Gamblin (QLD) will remain as Special Envoy, Employment and Business Services, and Ms Ruth Jacka (NSW) and Ms Christine Kerr (WA) have been appointed as Deputy Chairs for two years.

Safety Net

The following is an email exchange between Dr Elizabeth Sheedy (Vice-President of Learning to Learn in Sydney). Dr Sheedy recently contacted the Department of Health (Federal) to see if the new Safety Net arrangements could be useful for helping to fund treatment for her ASD son.

From: Elizabeth Sheedy

Sent: 06/01/2004 15:03

To: medicareplus@health.gov.au

Subject: Question re Safety Net

"The Council was established in 1996 and provides important advice on disability issues and strengthens the links between government and people with disabilities, their families and carers and service providers."

"The selection process for the new council members attracted over 1000 enquiries and 148 high quality applications.

"The selection criteria required the council to maintain an appropriate balance of experience and expertise including people with a direct and personal experience of disability; people who are family members and carers of people with a disability; and people with expertise in support services for people with a disability.

"The Government continues its commitment to improve services and support people with disabilities and to deliver these services to the highest possible standards.

"I would like to take the opportunity to thank retiring members for their valuable contributions to the work of the Council and look forward to working with the new Council," said Senator Patterson.

I am the mother of 5-year old Jonathan who has Autistic Spectrum Disorder. Following the direction of his paediatrician, Dr Nathalie Silove of Westmead Children's Hospital, we are treating him with an ABA program (applied behaviour analysis). ABA is the only treatment for autistic children that offers the chance of a "normal" life and which is based on sound scientific research.

While the program has been recommended by his paediatrician, the provider is not a medical practitioner. The provider is an organisation called Early Autism Project that specialises in treating autism using behavioural principles. The program is

costing us \$30,000 per annum. We receive no assistance through the state government.

Is it likely that the new Safety Net proposals could help us?

Similarly, would the Safety Net cover costs of private speech therapy for autistic children?

Regards,

Dr Elizabeth Sheedy

Artarmon

From: Health.Applications/Health@health.gov.au

Sent: Wednesday, 21 January 2004 10:01 AM

To: Elizabeth Sheedy

Subject: Re: Question re Safety Net

Dear Ms Sheedy,

Queensland

Autism care needs early intervention

By Tony Koch

<http://www.couriermail.news.com.au/printpage/0,5942,8518784,00.html> 3/02/2004

29jan04

Statistics dictate that of the several thousand Queensland children having their first day at pre-school this week, about 200 of them will be sufferers of autism.

These are the little ones who have difficulty relating, who seem aloof and unsmiling and are prone to obsessive behaviour.

Unless their affliction has been addressed for the past couple of years, they are about to enter a period of life that is frightening for them – and frustrating for their parents and teachers.

Highly regarded Brisbane oncologist James Morton and his wife Louise have a son Andrew, 4.

"By the time Andrew was about two, Louise picked up that he was slow to speak, very anxious and irritable. We couldn't take him out of the house. He would just sit in front of the television watching the same program over and over," Morton explains.

Thank you for your enquiry about MedicarePlus. You sought clarification of the type of medical expenses that would count towards the proposed MedicarePlus safety net.

The proposed MedicarePlus safety net applies to services listed on the Medicare Benefits Schedule (MBS) that are provided outside hospital.

Services provided by psychologists and speech therapists are not listed on the Medicare Benefits Schedule and, therefore, will not be covered by the proposed safety net.

Yours sincerely

MedicarePlus Implementation Team

Australian Government Department of Health and Ageing

medicareplus@health.gov.au

Morton had the advantage of knowing top specialists, and Andrew underwent medical examinations to find out the problems. Eventually, autism was diagnosed – which set his parents frantically in search of information on what could be done to help their child.

They tried several programs, some with success, others not so good – all endeavouring to equip Andrew with the necessary skills to cope with day-to-day life.

Most success came through a special education unit at Mt Gravatt, which was a pilot project of the State Government, but closed when the initial allocation of funds ran out.

"To fund the necessary therapy privately would be prohibitive to many families. My view is that every little child with autism should have these programs available," Morton says.

Getting treatment for their son brought the Mortons into contact with other parents of autistic children – and all were frustrated about where to go and what was best to do.

Morton, through personal studies of autism coupled with discussions with specialist medical colleagues, was convinced that early intervention therapy could

make a significant difference to the development of afflicted children.

Along with other parents and therapists, the Mortons have set up the Autism Early Intervention Outcomes Unit (AEIOU), which will provide the necessary therapy up to 30 hours a week for five children aged 18 months to six years, and the number of children will rise by five the following year as they get more established.

Eventually they want to have eight similar centres around Queensland, although that is still some time – and a lot of help – away.

Morton bought a former church building in Moorooka for \$440,000 to get the project off the ground. He and his wife are putting in \$100,000 in cash, and a benefactor is also weighing in with \$100,000.

They have asked the State Government – so far without success – to match the contributions they raise.

"It will cost about \$400,000 to get up and running for the first 18 months," Morton says.

"We eventually aim to be treating about 80 children a year, and it is a two-year program for each of them. At the end of that period, the aim would be transition to normal education services with lots of support."

Educational therapist Rebecca Allen will be in charge of the centre, which will provide individually tailored programs for the very young children.

"Children with autism learn at a different rate and in different ways from other children, and require a higher level of support than a regular kindergarten or preschool teacher is able to provide," Allen says.

"The therapy should take place in a small group to allow for extra attention, but still in a social, classroom environment. Presently many Queensland

children with autism who are having specialised treatment are doing so in their own homes, which doesn't provide adequate socialisation."

Morton says the actual cost is about \$33,000 per child for the program – which is way beyond most families.

But we are dealing with the man who introduced into Queensland the "Shave for a Cure Campaign" run by the Leukaemia Foundation (of which he is a board member), which raises millions each year.

"AEIOU is a registered charity and I have written to Premier Beattie asking for support and for the Government to match the funds we raise," Morton says.

"I envisage getting businesses eventually to put up \$25,000 a year each, which would be the full sponsorship cost for one child to go through the program for one year.

"We are not setting up in opposition to Autism Queensland, but see ourselves as complementing that excellent organisation. Our sole aim is to get children as early as possible on to the therapy so they can learn the skills they need.

"It is a very intensive program for very little children."

The situation is that AEIOU is waiting for a response from the State Government before it can get started, but everybody seems preoccupied with the election.

If you can help, or if you want information about the organisation, call AEIOU on 1800 283 800.

• Tony Koch is an assistant editor of *The Courier-Mail*.

kocht@qnp.newsltd.com.au

Awareness

The Sound Of Silence

[With apologies to Simon and Garfunkle.]

Hello autism, my old friend.

I've come to battle you again.
Because an insult softly creeping
Left its seeds while I was sleeping
And the insult that was planted in

his brain
Still remains
Within the sound of silence.

In restless dreams we walked
alone,
Narrow streets of cobblestone
'Neath the halo of a street lamp,
I held my son from the cold and
damp
When my eyes were stabbed by
the flash
of a neon light
That split the night
And touched the sound of silence.

And in the naked light I saw
Ten thousand children, maybe
more.
Children talking without
speaking,

Children hearing without
listening.
Children singing songs that
voices never shared,
No doctor dared
Disturb the sound of silence.

"Doc," said I, "you do not know,
Autism like a cancer grows.
Hear my words that I might teach
you,
Take my arms that I might reach
you."
But my words like silent
raindrops fell
And echoed in the wells of
silence.

And the doctors bowed and
prayed
To the pharma gods who paid
And the sign flashed out its
warning
In the words that it was forming.
And the sign said "The words of
the parents are
written often, loud and tall;
Emailed one and all:
Raging against the sound of
silence."

-By L. Schafer

Courtesy Schafer Report

Lifting the Veils of Autism, One by
One by One

By ERICA GOODE

February 24, 2004

[http://www.nytimes.com/2004/02/24/health/psychology/24AUTI.html?pagewanted=print&posit
ion=](http://www.nytimes.com/2004/02/24/health/psychology/24AUTI.html?pagewanted=print&position=)

He is blond and 3 years old, 33
pounds of compressed energy
wrapped in OshKosh overalls.

In an evaluation room at Yale's
Child Study Center, he ignores
Big Bird, pauses to watch the
bubbles that a social worker
blows through a wand, jumps up
and down. But it is the two-way
mirror that fascinates him,
drawing him back to stare into the
glass, to touch it, to lick it with
his tongue.

At 17 months, after several ear
infections and a bout of the flu,
the toddler's budding language
skills began to deteriorate, his
parents tell the evaluators. In the
playroom, he seems intent on his

own activities and largely
oblivious to the adults in the
room. Only when the therapist
bends down to tickle him does he
give a blinding smile and meet
her gaze with startling blue eyes.

Sixty years after it was first
identified, autism remains one of
the most puzzling of childhood
disorders. Its cause or causes are
still unknown. But in recent
years, investigators have begun to
dislodge some of its secrets.

Studies have offered clues to the
brain mechanisms that may lie
behind some features of autism
— the tendency to focus on
objects rather than human faces,
for example — and geneticists
have begun to home in on genes
that may be involved. Scanning
has provided glimpses of ways
autism may affect brain
development: the brains of
autistic children, studies find,
appear to be larger than normal
for some time after birth.

In the future, experts say, such
research may yield effective

medical treatments to augment or
even replace the intensive
behavioral therapy that is the
prescription most autistic children
now receive.

In learning more about autism, a
disorder that in some form affects
at least 425,000 Americans under
18, scientists may also increase
knowledge about language
development, emotion, even
friendship and love.

"Ultimately, research on autism
may teach us a lot about what it
means to be social," said Dr.
Thomas Insel, the director of the
National Institute of Mental
Health.

Autistic children were once
thought to have a form of
childhood schizophrenia. Prone to
repetitive, sometimes self-
destructive behaviors and driven
by "a powerful desire for
aloneness and sameness," as Dr.
Leo Kanner of Johns Hopkins put
it in a now classic 1943 paper,
they often spent their lives in
institutions. Parents watched

helplessly as their children disappeared into a world beyond their reach.

But much has changed. The notion that autism was caused by "refrigerator" mothers and absent fathers, promoted by psychoanalysts in the 1950's and 1960's, has yielded to the realization that the disorder is strongly rooted in genetics and abnormalities of brain development and function. Environmental influences early in life may also play a role.

At the same time, a sharp rise over the last decade in the number of autism cases diagnosed in the United States and other countries has raised public awareness and helped secure more government financing for research.

In the 2003 fiscal year, the National Institutes of Health spent an estimated \$81.3 million on autism research, compared with \$9.6 million in 1993.

The last two decades have brought a sea change in the way scientists view autism and those who suffer from it.

Researchers now recognize, for example, that autism is not synonymous with mental retardation: more than 80 percent of children with autism were once thought to be mentally retarded.

More recent estimates place the number at 70 percent, or lower if related disorders are included.

Dr. Kanner believed autism to be a product of upper-middle-class homes, a conclusion based on the children he examined, who were the progeny of doctors, lawyers and scientists. But it is now clear

that autism crosses class boundaries.

Boys are four times as likely as girls to have the disorder. This sex ratio has led one researcher, Dr. Simon Baron-Cohen, director of the autism research center at Cambridge University in England, to speculate that autism is a form of "extreme maleness," but the theory has yet to be supported by research.

More rigorous studies have allowed clinicians to identify autism in children of younger and younger ages. In the past, the disorder often was not diagnosed until children were 4 or 5. But by studying home movies of birthday parties or first baths, investigators have found telltale signs of autism in children of 12 months or younger.

Dr. Geraldine Dawson, director of the University of Washington's autism center, for example, studied infants from 8 to 10 months old who were later identified as autistic. The infants, she said, often failed to respond when parents called their names.

"Even very young babies, when you call their name, will turn and look at you," Dr. Dawson said.

As toddlers, autistic children show other differences. For example, they make eye contact less frequently, and, unlike most 1-year-olds, do not point at objects or people.

Autism's hallmarks are a delay in language development, an inability to relate to other people and stereotyped or rigid behavior. But researchers have found that children vary greatly in the nature

and the severity of their disabilities.

"If you put 100 people with autism in a room, the first thing that would strike you is how different they are," said Dr. Fred Volkmar, a professor of child psychiatry at Yale and an expert on autism. "The next thing that would strike you is the similarity."

Some children attend regular schools, others are so disabled they require institutional care. Some children speak fluently, others are mute. Some are completely withdrawn; others successfully navigate a path through the outer world.

In fact, studies show that many children with autism can improve with treatment, and some — from 15 to 20 percent, experts say — recover completely, holding jobs and living independent lives.

Yet the realization that autism takes many forms has also made its diagnosis more complicated. In 1994, psychiatrists added a new diagnostic category — Asperger's syndrome — to the psychiatric nomenclature, to take account of children who displayed some features of autism but did not meet the full diagnostic criteria.

Many researchers view Asperger's as distinct from autism. But the differences become blurred in cases where children have normal or above normal I.Q.'s. In such instances, experts say, whether Asperger's or autism is diagnosed is often arbitrary.

"I don't think anyone's got good evidence for a clear distinction

between people with high-functioning autism and Asperger's," said Dr. Tony Charman, a researcher in neurodevelopmental disorders at University College London.

The Disconnect Calculations, Yes; Eye Contact, No

As a child, Donald Jensen lay in bed at night, tracing numbers in the air with his finger. He memorized lottery numbers. He was riveted by the pages of the calendar.

Now 19, his facility with mathematical calculation seems magical. Given any date — Jan. 7, 1988, for example — he can, in an instant, identify the day of the week it fell on. (It was a Thursday.) He virtually never makes mistakes.

Yet even in childhood, there were signs that Donald was exceptional in other ways. He was mesmerized by the washing machine, becoming upset if the laundry was finished before he got up in the morning. He started talking late. Once, when his grandmother slipped on some ice in the yard and fell, he continued to chatter about numbers, seemingly oblivious to her plight.

Problems in school led doctors to diagnose autism when Donald was 6, his uncle, Glen Jensen, said. As an adult, Donald's gifts — he is among the 1 to 10 percent of people with autism known as autistic savants — connect him to the world. "What day were you born?" he asks visitors.

But the things that Donald cannot do also separate him from other people. He rarely makes eye

contact. Ask him how he calculates dates or what numbers mean to him and the inquiries are met with silence. His ability to empathize with other people has grown over the years — "John was angry today, and that was upsetting to me," he will say — but unexpected events disturb him, and his conversations sometimes take the form of asking questions over and over.

What lies at autism's core? Over the decades, researchers have come up with a variety of theories. But most were based on what clinicians observed, not on what might be going on in the brain. Only recently have sophisticated technologies allowed researchers to begin bridging the gap between the consulting room and the laboratory.

Dr. Ami Klin, an associate professor of child psychology and psychiatry at Yale, and his colleagues began with the observation that people with autism often have a great deal of intellectual knowledge, but lack "street smarts," and are unable to use what they know in social situations.

"Many of our clients know the currencies of all countries in the world, but they cannot go to McDonald's and buy a burger and count the change," Dr. Klin said. "They know all the bus ramps, but can't take a bus."

In a series of experiments to find out why it is so difficult for someone with autism to function in the world, the Yale team, including Warren Jones, a research associate, developed a device for tracking eye

movements that could be mounted on the brim of a baseball cap. Then they had subjects, who either had autism or did not, watch a video clip from the 1967 film "Who's Afraid of Virginia Woolf" and monitored their gaze.

The normal subjects closely tracked the social interactions among the actors in the films, focusing especially on the actors' eyes. In contrast, people with autism focused on objects in the room, on various parts of the actors' bodies and on the actors' mouths.

In one scene, Richard Burton and Elizabeth Taylor kiss. The subjects without autism looked at the actors' embrace; the autistic subjects' eyes went elsewhere: one man stared at a doorknob in the background.

Such research suggests that from birth, the brains of autistic children are wired differently, shaping their perception of the world and other people. "In normal development," he said, "being looked at, being in the presence of another, seeking another — most of what people consider important emerges from this mutually reinforcing choreography between child and adult."

If this duet cannot take place, Dr. Klin said, "development is going to be derailed."

Studies using brain scanning techniques like fast M.R.I. lend weight to the idea that for people with autism, perception molds behavior.

"There is a deep relationship between what we see and what we know," said Dr. Robert

Schultz, an associate professor at Yale's Child Study Center.

Researchers have long known, for example, that people with autism have difficulty recognizing faces. In non-autistic subjects, a brain area called the fusiform gyrus is activated in response to the human face. But when pictures of unfamiliar faces are shown to children or adults with autism, studies show, the region is less active.

Dr. Schultz said that autistic people appear to identify faces the way other people identify objects, by piecing features together. While most people are better at recognizing images of faces when they are right-side up, autistic subjects identify them faster when they are upside-down.

A recent study, presented at the annual meeting of the American Association for the Advancement of Science in Seattle this month, illustrates this. Dr. Dawson, of the University of Washington, and a colleague reported that when autistic adolescents and adults were shown pictures of faces, another brain area involved with object recognition was activated, while the fusiform gyrus remained quiet. Yet when the researchers showed photos of the subjects' mothers, the fusiform brain did light up.

Work by Dr. Isabel Gauthier, an assistant professor of psychology at Vanderbilt University, suggests that, in fact, the fusiform gyrus is not programmed to react to faces per se but to things that people care about and learn to distinguish in detail.

Dr. Gauthier trained people to become experts on "greebles," a class of simply-drawn imaginary beings. When the subjects became adept at telling one greeble from another, she found, the fusiform gyrus lighted up in response to pictures of the creatures. Similarly, when car experts were asked to identify different car models, the region was activated, Dr. Gauthier reported last year in the journal *Nature*.

The research suggests that children with autism can be trained to become better at face recognition — something that scientists at Yale and other universities are trying. But the seeming indifference to the human face that often accompanies autism has led the Yale researchers to propose that the fusiform gyrus may be a component of the social brain, intimately tied up with basic emotional responses like fear, anxiety and love.

In fact, some studies have found abnormalities in the amygdala, a brain region involved with emotion and social awareness. But the findings are inconclusive, and differences in autistic brains have been found in structure, including the temporal lobes and the cerebellum.

The Physical A Telling Find: Bigger Brains

In his early description of autism, Dr. Kanner noted that heads of the children were larger than normal. Modern researchers have confirmed this observation, finding that for some period of time during childhood, autistic children have bigger brains than

their non-autistic counterparts. In 2001, Dr. Eric Courchesne, a professor of neuroscience at the University of California at San Diego, and his colleagues found that 4-year-olds with autism showed increases in the volume of the brain's gray matter, where the cell bodies of neurons are located, and white matter, which contains nerve fibers sheathed with an insulating substance called myelin.

In a 2003 study in *The Journal of the American Medical Association*, Dr. Courchesne reported that at birth, the heads of infants with autism were smaller than normal, but then showed "sudden and excessive" growth in size from 1 to 2 months and from 6 to 14 months. By adolescence, however, the children's brains were the same size as those of other children or slightly smaller.

Dr. Martha Herbert, an instructor in pediatric neurology at Harvard, has begun to zero in on precisely where this growth spurt occurs. At the annual meeting of the Society for Neuroscience in October, she reported that in autistic children, the outer zones of white matter became enlarged compared with normal brains beginning after age 6 months and continuing into the second year of life. Those outer zones, Dr. Herbert said, are insulated later in development than the areas of white matter deeper in the brain.

"It seems that something is going on that gets more intense," Dr. Herbert said.

In another study, Dr. Manuel Casanova, a professor of neurology and neuropathology at the University of Louisville,

found an increase in autistic brains in the stacks of neurons known as mini-columns that extend through the layers of the neocortex. The brains of people with autism not only had more mini-columns, Dr. Casanova found, but the neurons that made up the columns were less variable in size than in normal brains.

Such findings are intriguing, but their meaning is not clear.

One possibility is that the enlargement in white matter reflects an overabundance of myelin, which could disrupt the timing of communication signals throughout the brain. But this growth in volume, Dr. Herbert said, could also represent an increase in nerve fibers, the migration of other types of cells or some type of inflammation.

Dr. Casanova, for his part, theorizes that the proliferation of mini-columns might result in a deluge of stimulation, or as he puts it, "way too much information."

"The sound of rain on a roof might seem like driving nails into a tin roof, a fluorescent light might become extremely perturbing," Dr. Casanova said.

Dr. Nancy Minshew, a professor of psychiatry and neurology at the University of Pittsburgh, argues that autism's core lies in higher brain areas, rather than in deeper structures that govern emotion.

"When I started about 20 years ago, I looked at autism and said this disorder is in the cortex of the brain," Dr. Minshew said. "It's the classical disorder of cognition."

The Genetics: Child Rearing Not at Fault

In 1964, Bernard Rimland, a British psychologist with an autistic son, put forward the view, then controversial, that genes, not faulty child rearing, lay behind the disorder.

Most experts now agree that autism is strongly determined by heredity. Studies indicate, for example, that if parents have one child with autism, the chance that they will have a second autistic child is 2 to 6 percent — about 100 times the general risk.

Twin studies also argue for a large genetic component. Identical twins, the studies suggest, run a 60 to 85 percent chance of having autism or a similar disorder if their twins have it. For fraternal twins, the chances are 10 percent.

Two very rare forms of autism — one associated with the congenital disease known as tuberous sclerosis and the other with fragile X syndrome — are known to be caused by chromosomal defects.

But in most cases, autism is thought to have a more complex genetic origin, involving multiple genes acting together.

"The bulk of people with autism develop it because they have inherited a particular genetic predisposition," said Dr. Anthony Bailey, a professor of psychiatry at Cambridge.

Finding those genes, however, is a difficult task. The disorder is relatively uncommon, and most people with autism do not have children, making it difficult to track successive generations of a family.

To get around these obstacles, some researchers are studying families having two or more members with autism and searching for similarities in the genome that could provide the crucial link to the disorder.

Cure Autism Now, an advocacy group based in Los Angeles, has started a program to collect DNA samples from such families and use them for research.

Large-scale studies are in progress at a variety of institutions in the United States and other countries. DeCode Genetics, an Icelandic company that last year identified a gene that may contribute to schizophrenia, announced in January that it would use the Icelandic population to search for genes underlying autism and similar disorders like Asperger's.

Some researchers are also hunting for genes that may underlie specific aspects of autism.

Dr. Daniel Geschwind, director of the neurogenetics program at the University of California, Los Angeles is hoping, in a study of autistic children and their families, to find genes that contribute to the delayed development of language.

No specific gene for autism has yet been pinpointed. But promising areas have been identified on a variety of chromosomes, including the 2, 3, 7, 13, 15 and the X chromosome.

"My sense is that we are close to the tipping point in this illness," said Dr. Insel of the National Institute of Mental Health, "and that over the next couple of years we will have, not all of the genes,

but many of the genes that contribute."

At the same time, the disorder is not entirely genetic, indicating that some environmental influences, either during a mother's pregnancy or in the first years of life, have roles in setting off the disorder, perhaps by changing the way genes function without actually altering DNA.

Over the years, many candidates have been proposed, including German measles during pregnancy; yeast infections; the sedative drug thalidomide; childhood vaccines; viruses; the labor-inducing drug Pitocin; and dietary, hormonal or immune

system changes during pregnancy.

But so far, researchers say, solid evidence for any single factor has not emerged. Still, several research groups are trying to address the issue of environmental triggers. A study based at Columbia University, for example, will follow 100,000 pregnancies in Norway, examining a variety of environmental influences, including infections, vaccinations, mercury exposure and prenatal stresses.

Experts disagree about the importance of environmental influences. But there is a

consensus that autism probably has more than one cause, its symptoms the common end point of different biological pathways.

Yet it may be some years, experts say, before scientists are able to link the findings from genetic studies and brain research with the outer signs of the perplexing world that people with autism inhabit.

When it comes to autism, said Dr. David Amaral, a professor of psychiatry at the University of California at Davis, "In many respects, we're still in the dark ages."

Research

Autism Society of America

ASA-Net The Autism Society of America's e-Newsletter February 15, 2004

Vaccine Safety Panel Holds Meeting on Vaccines & Autism; Group Expected to Release Report in May 2004

A national panel charged with advising the government on the safety of vaccines met this week in Washington, DC, to address the topic of vaccines and autism. The Immunization Safety Review Committee, which falls under the auspices of the National Academy of Sciences' Institute of Medicine and is made up of 15 independent scientists from across the country, heard researchers from the public and private sectors present evidence for and against a causal relationship between vaccines and autism.

The panel last met in 2001 and reported at that time that there did not appear to be a causal link between vaccines and autism, but added that more research needed to be done. The panel met again this past Monday, February 9, to review the current research on the issue. Speakers included a Member of

Congress, two government researchers from the Centers for Disease Control and Prevention and the National Institute of Allergy and Infectious Diseases, six university researchers, three international scientists (from Canada, the United Kingdom, and Denmark), and two other independent researchers.

Most of the presentations addressed the potential link between thimerosal (a mercury preservative formerly found in some childhood vaccines and still in some vaccines today) and autism. The researchers who presented evidence based on several large-scale epidemiological studies concluded that there was no evidence of a causal link between vaccines and autism, while the scientists who presented evidence based on more clinically based studies said there was a connection for a subgroup of individuals who are genetically susceptible. The latter group proposed that some children with autism, because of their genetic makeup, are unable to process mercury from their bodies and the result was neurological damage, specifically autism. Members of the public who were unable to attend or were unable to

ask questions at the meeting due to time restrictions are invited to submit comments to the panel in writing by Monday, February 16, 2004. For information on how to submit feedback or for more information about the meeting, please visit the Institute of Medicine's Web site (www.iom.edu) and do a search for "autism meeting nine." PowerPoint presentations are also available on the Web site, and audiotapes will be available soon.

http://www.autism-society.org/site/R?i=PNFQxWmqDo_slMX1I3B5YQ

The group is expected to release their second report on the issue in May 2004. Stay tuned to the ASA-Net and to the ASA Web site for an update on that report when it is made available. To access the full ASA article on the meeting, please go to the ASA Web site and click on "News."

Studies on Vaccines & Autism Appear in February Journals

Two new studies on the relationship between vaccines and autism appear in the February issues of two scientific journals. One is a population-based study on the comparison of the age at which children with and without autism received their MMR vaccine. The other study addresses the relationship between the preservative thimerosal and developmental disabilities.

1) The first study, which was conducted by researchers at the Centers for Disease Control and Prevention, appears in the February issue of the journal *Pediatrics*. According to the journal article, the objective of the study was "to compare ages at first measles-mumps-rubella (MMR) vaccination between children with autism and children who do not have autism." According to the article, the study was based on the hypothesis that "...earlier age at vaccination, ie, before a possible critical time window for autism development, might be associated with an increased risk for autism."

However, the article indicates that the study did not find the hypothesis to be true. According to the study's conclusion, "From a large population-based case-control study that included well-defined case group and a comparison group of children selected from the same community, we found that, overall, the age at time of first MMR administration was similar among case and control children." To view the article, visit the journal's Web site (www.pediatrics.org) and do a search for "autism" in the year "2004."

2) The second study, which was conducted by researchers at Northeastern University, appears in the February issue of the journal *Molecular Psychiatry*. According to Northeastern University, which announced the study, "there appears to be a link between exposure to certain neurodevelopmental toxins and an increased possibility of development neurological disorders including autism and attention-deficit hyperactivity disorder."

In addition, Northeastern said, "Though some speculation exists regarding this link, Deth [the study's lead author] and his colleagues found that exposure to toxins, such as ethanol and heavy metals (including lead, aluminum and the ethylmercury-containing preservative thimerosal) potentially interrupt growth factor signaling, causing adverse effects on methylation reactions (ie, the transfer of carbon atoms). Methylation, in turn, plays a significant role in regulating DNA function and gene expression, and is critical to proper neurological development in infants and children." To view the article, visit Northeastern University's Web site (www.northeastern.edu) and search through their news options.

ASA-Net is created by the Autism Society of America. Autism Society of America 7910 Woodmont Avenue Suite 300 Bethesda, MD 20814-3067 1.800.3AUTISM www.autism-society.org

Diary Dates

AUTISM SPECTRUM
DISORDER CONFERENCE

24th & 25th March 2004

Jupiter's Casino Townsville

Hosted by: North Queensland
Disability Training Coalition

The Disability Sector Training
Fund is a project of the
Queensland Community Services
& Health Industries Training
Council and funded by Disability
Services Queensland

The conference aims to provide
an opportunity for those attending
to gain up to date information on
assessment, intervention and
management of ASD.

Recognising the difficulty
regional centres experience in
accessing such information has
prompted the coalition to provide
this localised conference. The
coalition also hopes to increase
awareness of ASD for the
community in general and for
those people required to play a
significant role in the lives of
people with ASD.

Topics: Communication,
Nutrition, Intervention,
Residential Needs, Anxiety and
ASD, Coping and Stress, Schools,
Families and Doctors working
together.

Presenters: Some of the
presenters include: Jane
Remington-Gurney, Dr Robyn
Cosford, Dr Gary Deed, Dr
Michael McDowell and many
more!

Registration Fee: (includes
morning tea, lunch and afternoon
tea both days)

- Parents & Unpaid Carers of
People with a Disability – \$25
(includes both days)
- DSQ Funded service
providers - \$25 (includes both
days)
- Others \$250 (includes both
days)

Registration Closing Date: 10th
March 2004

**A Special Note to Parents &
Carers:** Parents & Carers
wanting to attend the conference
are encouraged to contact the
Project Officer, Gabrielle Tidey-
Passlow to discuss, in confidence,
any difficulties or special needs
that may prevent attendance at the
conference.

Enquires: Gabrielle Tidey-
Passlow 07 3234 0190

The 2004 Autism Conference

14 & 15 May 2004

Brisbane Technology Park
Conference Centre

ABIQ is proud to be working
along side Jesse.ka, Autism
Queensland Inc. and Disability
Services Queensland to bring to
you The 2004 Autism Conference
in conjunction with the National
Autism Awareness Week 2004.

The theme of the conference will
be "Reach for the Stars",
reflecting the belief that children
with ASD have boundless
potential to achieve.

Presentations will cover a range
of treatment approaches enabling
families, carers and professionals

to become better informed about
how to assist the child with ASD
to reach his or her full potential.

The conference has so far secured
the following world-renown
professionals to deliver keynote
presentations: **Dr Tony Attwood;**
Dr Doreen Granpeesheh;
Donna Williams; Dr Anthony
Underwood; Stephen Shore;
Amy B. Laurent; Tracy Bester.
Other presenters at the 2004
Autism Conference will include
Dr Lawrie Bartak, Jane
Remington-Gurney, Annette
O'Sullivan, Julie Wallace, Dr
Daniel Markovich, Dr Gary Deed,
Jeanie Ryan, Dr Devin Houston,
Dr Sylvia Rodger, Marcy
McCarthy, Mark Darling, Natalie
Swayn, Holly Brennon, Helen
Merry, Jacinta Costello, Jill
Ireland, Maryann Kerr, Kylie
Walsh and many others.

The 2004 Autism Conference is
an event not to be missed.

Carerfest 2004

Three day Carers Retreat

Monday March 22, Tuesday
March 23 and Wednesday
March 24 2004

Carers from the Southern
Highlands region will gather for a
program of workshops and guest
speakers. Also provided, is an
expo of services, equipment and
aids and a pampering program.

The program will take place in
Queanbeyan, NSW.

The programs aim is to enhance
caring relationships by providing,
education, information, practical

skills and respite in a relaxed and friendly environment.

The focus of Carer-Fest has been developed to provide an environment of relaxation, information and peer-group support. Additionally Carers will have the opportunity to;

- Network and have quality contact with other Carers.
- Have an opportunity to receive information in a relaxed/get-away style.
- Have the opportunity to be pampered and to focus on

relaxation and stress reduction.

- Have an opportunity to interact with services providers in a recreational setting

The program is divided into four streams and they are.

- A program of workshops
- The expo program
- The guest speaker program
- The pampering/relaxation program

Some guest speakers and workshop leaders also provided one on one consultation to individual Carers as part of their service to the program.

**Contact: Lee-Anne Duncan
(Commonwealth Carer Respite
Centre - Southern Highlands)
02 62984529 (w)**

November Profile

Jo Heard is one half of the A4 Editorial team responsible for bring the A4 Update to the readers each month. She kindly agreed to be 'profiled' for this issue of the Update.

NAME?

Josephine - usually known as Jo

BORN?

Melbourne

LIVES?

Melbourne

FAMILY?

Married to Peter, children William 13, Nicholas 10, Georgina 5, Emily 5 and Dominic 5.

INVOLVEMENT WITH A4?

Co-editor of the Update

OTHER ORGANIZATIONS?

AFSA

DREAMING OF?

sleep

LISTENING TO?

Opera – preferably by Puccini

READING?

The weekend newspapers

RELAXING?

Brain chill out time at the gym

EATING?

Nudel Bar in Bourke St have a great potato curry served with roti

LIKES?

Enjoying life

IDEAL WEEKEND?

Relaxing family time

LAST HOLIDAY?

Sydney January 2004