

Contact



Gary and Temple Launch PAPA Training Portfolio



TRAINING

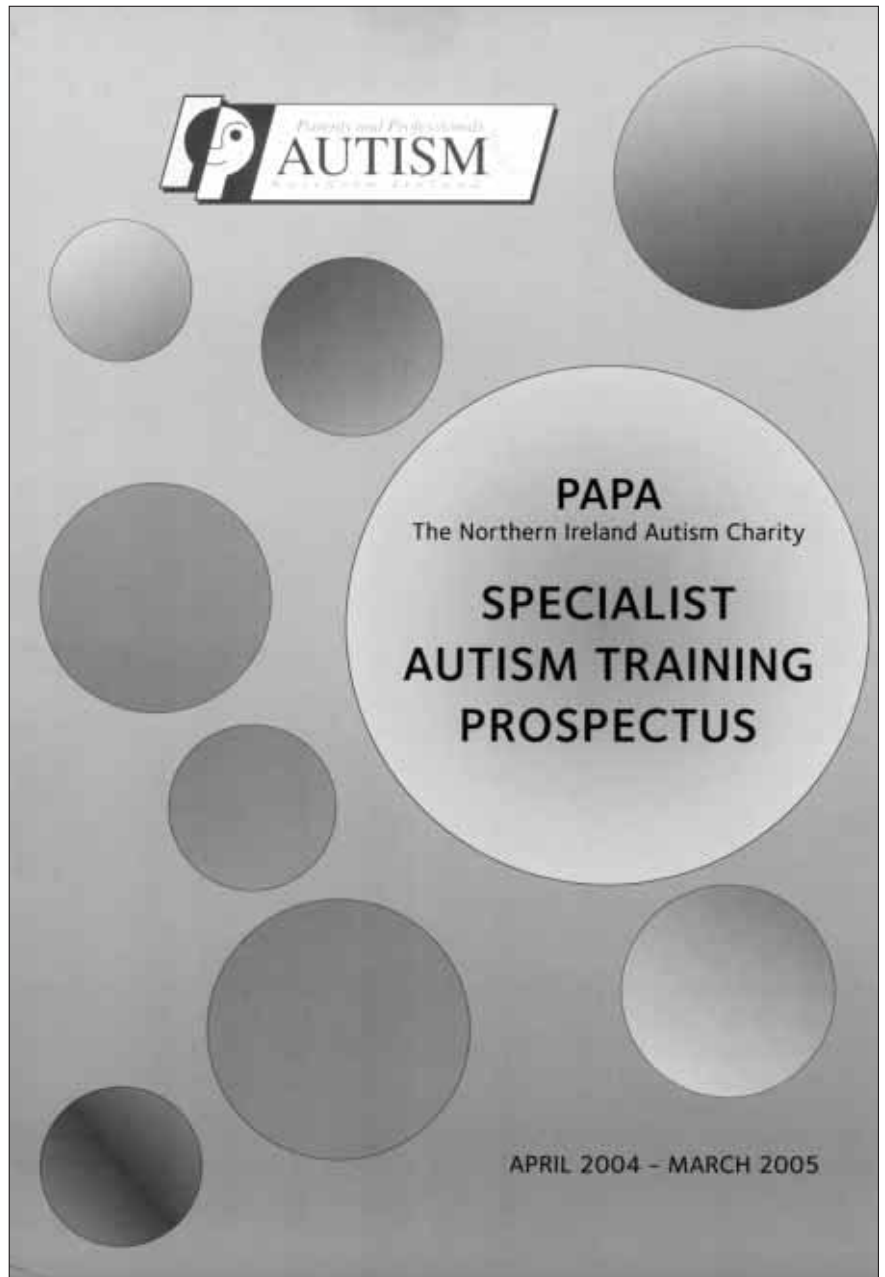
PAPA opened its doors to hundreds of eager trainees as it launched its pilot training scheme with three Education & Library Boards. This training was directed at both parents and professionals with the majority of training being delivered over an intense 4 month period throughout three Board areas – January to April.

The training partnership between PAPA, North Eastern Education & Library Board, Western Education & Library Board and Belfast Education & Library Board stemmed from recommendations made in the Task Group on Autism Report which was published in April 2002.

The report highlighted the increasing prevalence of Autistic Spectrum Disorders in Northern Ireland as well as gaps in services, professional expertise and parental support. In recognition of these training and support needs, the three Boards approached PAPA to establish a partnership. PAPA welcomed this as being a very significant step forward, by the Boards, in addressing the needs of parents and professionals who live and work with individuals with an Autistic Spectrum Disorder.

In addition to organising and delivering this training PAPA was working on creating its own Specialist Autism Training Prospectus, the deadline for which being the Colours of the Spectrum Conference on 1 April 2004.

This project was assigned to Jackie Addis, PAPA Development Officer Training and Gillian Henderson, PAPA Admin Project Officer Training. It produced many a grey hair on both their heads but the deadline was met and both launch and conference were highly successful.



The Training Prospectus and flyers have been sent to PAPA members, PAPA Branches, Voluntary organisations, Statutory organisations and School throughout Ireland both North and South. It has also been incorporated onto the PAPA website – www.autismni.org/training – with a downloadable booking form for convenience. PAPA is continuing to liaise with voluntary and statutory organisations regarding recurrently funded places.

The training included in the prospectus is given on page three. The quotes are from evaluations of training completed for the Education & Library Boards.

TRAINING

Fundamentals of Autism (General Awareness)
Fundamentals of Asperger's Syndrome
Asperger's Syndrome and Mental Health
ASD and Employment Issues
The Principles of TEACCH – An Introduction
The Principles of TEACCH – Practical Focus
TEACCH Professional Training
TEACCH Parent Training



"..... very enjoyable presentation by people who are obviously very committed to their work"

"..... excellent course which, for me, met all of its objectives"

".....extremely helpful in providing enlightenment on a fascinating area".

Autism & You Parent Training
Parent Discussion Workshop
A Multi-Element Applied Behavioural Analysis approach to Managing Behaviour
The Process of Diagnosis/ Assessment and Screening
The Use of Social Stories/Social Skills Training
The Use of Assessment Schedules (PEP-R)
Preparation for the Transition from Primary to Secondary Education

".....a very informative insight into the world of Autism"

".....excellent delivery and very clear presentation"

".....language used was easy to understand – no mumbo jumbo – which gave us a sound insight into ASD".

Keyhole Early Intervention Pre-School Training Package
Picture Exchange Communication Systems (PECS)
IABA (Autism ABA Model)
ICON to I CAN
Intensive Interaction Workshop
Managing Incidents of Challenging Behaviour
SMILE Interactive Play for Children with an ASD
Living with Special Kids



".....demanded and received attention/interest of participants"

".....relaxed atmosphere"

".....tutors were great – they helped make the course interesting and fun"

".....attendees would leave the course thinking 'Yes I can try that!'"

UNLIKELY HEROES

2004 was the largest Autism Conference ever staged in Ireland and as ever very informative. It's always a dilemma what to leave out in summaries but in this case it was made easier as both speakers were keen to get some points across, so if I'll just concentrate on trying to highlight those in this abridgement.

Why it is so important to give Autistic Spectrum Disorder (ASD) such special consideration.

different processing systems rather than having a damaged brain. Never the less they must live in "our world" where we keep trying to put round pegs in square holes. Mesibov thinks, "Its neat" to refer to people with ASD as coming from another culture. However he reports that people with ASD are quick to say that this analogy is alright as far as it goes, but they (and this Includes Temple Grandin) think of themselves not just from another background but another planet.

Torchlight

Another analogy Mesibov spent some time on was the torch. By adjusting the beam of a hand torch we can either have some light shining intensely over a small area or illuminating more dimly over a bigger area. People with ASD are like the former, and sense much smaller bits of information but in much more detail. Those of us who have a "wider beam" can absorb many bits of information which as we perceive in context, integrate them. However, with ASD, people tend to, for example, either see or hear and try to make sense of a world overloading their brains. Everyday living is forever assaulting their systems with too much information. On an extract of a film Mesibov let people with ASD describe for themselves what that was like. One person described his own sensory

Report on Colours of The Spectrum Conference

problems. To him coping was like filtered coffee. The filter's efficiency depended upon his stress levels. Our jobs as carers whether parented or professional, is to make sure their environment hasn't got "too much coffee" and care for them to help their "filters" stay effective.

Visual

- **Musical and Mathematical**
- **Verbal logic**

Temple is herself a visual thinker, being able to imagine clearly in 3-D, down to the smallest detail complicated cattle handling equipment that she has designed. Her brain is like "Google® for images". She can call to mind images lined up in a series, search engine fashion but she assures us it is hard to form a concept from a series of slides and only acquired after years of practise.

Observation of behaviour

- **Structured teaching**
- **Use of reinforcements**

Where they differ and what the choice must be based on is their outcome. TEACCH's philosophy, widely used in its literature is to make life *meaningful* for the person with ASD. The outcome for those with ABA is for "*normalisation*". The former is concerned with how the person feels about the world and the latter how the world feels about him.



PAPA North Down & Ards meet Temple Grandin

UNLIKELY HEROES

Mesibov in his Wednesday night address showed a clip from a French production company a film about the development of TEACCH. My imagination went off at a tangent I have to say. What if Hollywood were to make a film about the delivery of services for Autism? For sure, Mesibov would not be cast in this part; no, probably George Clooney or Harrison Ford. In any case somebody altogether more dynamic and strident, no heroes and heroines in Hollywood aren't quietly spoken and self-effacing, but I now come to realise they are in real life. Another common quality probably the most important to success of all is Altruism. To want to do something to for the sake of doing it rather than to tick your CV would seem vital. Temple tells us that she "is her job". Without it there is no meaning. Perhaps that is true for Mesibov. He commented on the advances he'd noticed in Northern Ireland since his first visit

Report on Colours of The Spectrum Conference

twelve years ago. I can't help thinking that that is due in part because we've been blessed with unselfish people doing their best.

BUILDING BRIDGES

Let me finish with a quote Mesibov finished with from Jim Sinclair:

"But my personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and I have no wish to be cured of being myself. If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms--recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us".

– Jim Sinclair, 1989

Review by Eilish Stocks



Author of this report Eilish Stocks along with GERALYN WOODS and DIANE HEYBURN meet with GARY MESIBOV

PAPA Launch Mental Health Booklet

March 12 at the Ramada Hotel Shaws Bridge marked the launch of a new PAPA Information Booklet. "Wake up to Asperger's Syndrome."

The Booklet was produced in partnership with the Department of Health Social Services and Public Safety and is the latest in PAPA'S expanding range of information resources.

The booklet is aimed at Mental Health Professionals, however is readable and understandable to anyone with an interest in this area. It covers the Triad of Impairments, gives a brief explanation what Asperger's Syndrome is, includes a number of clinical practice points and Gillberg's Diagnostic Criterion.

The second half of the booklet provides further information into specific mental health problems and their presentation within Asperger's Syndrome, and a reading list is provided with further information.

The booklet was produced in response to a recognised and growing need for information for Mental Health Professionals, and is part of PAPA's ongoing commitment to improve existing provisions for Autistic Spectrum Disorders and to provide the impetus for new provision.

PAPA wish to thank Dr Judith Gould, Dr Noel McCune, and Professor Michael Fitzgerald for their guidance and advice during the production of this Booklet

Wake up to Asperger's Syndrome is available from PAPA Central Office for a nominal fee of 50p



Wake up to Asperger's Syndrome

An Issue for Mental Health Services

This Booklet aims to

- Raise your awareness of Asperger's Syndrome as a mental health issue
- Inform mental health professionals about Asperger's Syndrome
- Provide basic information on diagnosis
- Provide information on treatment options
- Provide sources for further reading and information

The Booklet launch occurred within the wider context of "Wake up to Autistic Spectrum Disorder"

A conference hosted by Craigavon and Banbridge Trust and PAPA.

The conference theme was the provision of services for individuals with Asperger's Syndrome.

Conference Speakers were Terry Brugha Professor of Psychiatry at Leicester University, Dr Judith Gould Clinical Psychologist National Autistic Society, Patricia Beaddie who is a Person with Asperger's Syndrome and a PAPA Board Member.



POEMS AND STORIES

My Brother James

I have a little brother
and his name is James,
he has a thing called autism,
which means he doesn't think the same.
Although he may think differently
I love him very much.
In his world there is room for no mess, structure and order
is what he likes I guess

His clothes have to be perfect,
not a thread out of place,
he is not so fussy on haircuts,
but he likes to have a clean shiny face.
My mum and dad are very understanding
and acknowledging his thoughts and fears
I too do my best but its going to take years

We share our toys and have fun at the caravan,
but I worry about him when he becomes to be a man.
Who will look after him? Who will care?
I hope to protect him from those who snigger and stare.

The thing called autism affects all the family, I feel so
lucky that James was sent to me.

By Chloe Harrison age 8

My Brother Jake

My name is Jennie McGuigan. I have a little brother called Jake. Jake has autism so we have to do special things with him. The luckiest thing about that is Jake gets a trampoline!!

Everyone might think he needs to be treated specially, but to me he seems like a normal 3 year old, running around, playing and being very hyperactive!

The worst thing he did to me was he scabbed me on the cheek and I was crying, so it stung really badly.

I like giving him piggybacks and he enjoys them so much I normally get choked trying to get away!
Jake loves Coke, milk, Frobes and Jammy Dodgers He's so funny when he gives you dirty looks and he's cute when he smiles and sings Misfit and EIEIO

By Jennie McGuigan aged 9

Sound Bites from the Spectrum

"Mum I am like a noun, I like being and everyone else are verbs!
They like doing"

Please keep your stories and poems and anything else you wish to contribute coming in
Address: The Editor PAPA, Donard, Knockbracken Healthcare Park,
Belfast BT8 8BH

STRATEGIC PLANNING WEEKEND

Friday 12 – Saturday 13 March 2004

Mid March and its back to the Rural College again, for PAPA's annual Strategic Planning Weekend. As always the venue is an ideal location for a Spring Retreat to bring together the hearts and minds of PAPA and plan for the years ahead.

The weekend was well attended with only a few Branches without representation, and at 6pm the annual proceedings got underway. Branches represented:

Mid Ulster, Down, Newry and Mourne, Craigavon and Banbridge, Dungannon and Armagh, Omagh, Belfast South, Belfast West, Lisburn, North Coast, East Antrim and Derry.

For those of you unfamiliar with the Strategic Planning Weekend basically it brings together Council, Board, and Staff to ruminate on what has been, and to plan for what will be.

2003/2004 was a very successful year for PAPA. In this year we have initiated new projects, pioneered an early intervention model, published new information, and hosted some of the major names in autism. Thus it was anticipated this would be a positive experience for all.

PAPA staff came direct from the "Wake Up To Autism Conference" in Belfast hosted by Craigavon and Banbridge Trust. At this event we launched the latest of our information booklets "Wake up to Autism" but more about this on page 6.

The evening commenced promptly at 6pm with PAPA Chair Liz Aiken working through the new draft Strategic Plan. This new Strategic Plan aims to take PAPA into 2007, learning from and building on the successful and indeed not so successful aims and objectives of the previous Strategic Plan.

Council and Board Members had already had a chance to view the Plan prior to the weekend.

Issues raised and addressed on the first evening:

1. Derry and Omagh Branches highlighted their concerns regarding training and events being centred mostly in Belfast. The 9am start for training is also inconvenient for individuals living far from Belfast. Arlene and Liz assured concerned Branches that this concern would be addressed. PAPA Trainers are prepared to travel, but a minimum number of delegates are required in these circumstances. Details of this are available in the PAPA Training Portfolio.
2. An annual audit of Branch activities is to be considered, possibly at AGM time.
3. Listening and Responding Skills to be delivered once a year to Branches. Branches need to set a time aside for this, and approach central office to organise a trainer to go out and deliver this.
4. Branches are encouraged to contribute to the Newsletter.
5. Professionals to be encouraged to attend branch meetings
6. Training can be delivered in the evening to suit working parents
7. Sinn Fein to be approached for an Autism Ambassador
8. Communication and the lack of it needs to be addressed as part of the new Strategic Plan
9. Key Branch members to be trained in PR
10. Funding of parent places in conferences. PAPA generally does not organise conferences for profit. Places are already heavily subsidised by PAPA Central. Parental concerns about funding places taken on board, and PAPA Central to consider further subsidising places, and Branch members encouraged to approach their committee members for help with conference costs.

The Evening Session was constructive, and positive, breaking for the evening meal after 8pm.

STRATEGIC PLANNING WEEKEND

Friday 12 – Saturday 13 March 2004

Next morning it was bright and early for a day long workshop on developing a new communication strategy for PAPA.

The delegates worked closely with PAPA's Public Relations advisor Una McSorley to hammer out a Communications Strategy to ensure that PAPA's profile rises in tandem with our work rate and achievements. The new Communications Strategy as decided on the 13th of March will be arriving at a PAPA Branch near you soon!

The Strategic Planning weekend is a perennial touchstone in the life of PAPA it marks the end of one planning year and the commencement of the next. Offering an opportunity to look back over our shoulders at achievements made in the previous year, and forward to the challenges in front of us.

2003/2004 has been a resoundingly successful year for PAPA, and the staff wish to thank all the PAPA Board and Council members who acknowledged this, and complimented the staff on their creativity and energy. It is from looking back over our achievements in this year that we all draw strength to meet head on the challenges of the future. So as a boost for our collective moral read the list of our achievements this year, and give yourself a pat on the back!

- PAPA Staff invited to Downing Street to be personally congratulated by the PM for work achieved in N Ireland
- PAPA Develop new information pack
- PAPA Delegation meet with Jane Kennedy to lobby for funding to implement the recommendations of the Task Group Report
- PAPA host successful Conference to launch findings of Keyhole, this is later referred to in Good Autism Practise, and has generated instruction manuals, and is on the way to be patented as PAPA's early intervention approach
- PAPA employ Early Intervention Development Officer to pioneer home based intervention in N Ireland
- PAPA Facilitate meeting between LEAP (London Early Autism Project) and local education officials
- PAPA have ongoing contact with Mental Health Commission
- PAPA host Dept of Education launch of CD-ROM and Video, the culmination of a successful partnership
- PAPA's Bid to the Childrens Fund is successful and the WASP (Western Area Support Project for Children with Autistic Spectrum Disorder) gets underway
- PAPA host Lorna Wing and Judith Gould for AGM, opening of new premises, and launch of GP Information booklet, event is attended by Castlereagh Lord Mayor, and representatives from all the major political parties.
- PAPA Facilitate annual 5 Day TEACCH which is over subscribed as usual
- PAPA begin to develop a research relationship with Trinity College Dublin
- PAPA send a delegate to the Autism Europe Conference in Lisbon
- PAPA Host ICON-ICAN workshops in Donard
- PAPA organises and co-ordinates a fact-finding mission to New York for local professionals.
- PAPA begins 3 Month Intensive Training Pilot with 3 ELB delivering training to education as a result of the recommendations made by the Task Group Report
- PAPA Launch new information booklet "Wake up to Asperger's Syndrome" at Craigavon and Banbridge Trust Conference "Wake up to Autistic Spectrum Disorder" the booklet is the result of successful collaboration between PAPA and the DHSSPS
- PAPA Appoint Early Intervention Therapist for the WASP

Continued next page >

STRATEGIC PLANNING WEEKEND

Friday 12 – Saturday 13 March 2004

- PAPA host Gary Mesibov and Temple Grandin, for the largest yet Autism conference in Belfast. PAPA's Training Portfolio is also launched at this event.
- PAPA's Training Portfolio in circulation around N Ireland and beyond.

Perhaps the most gratifying thing of all for PAPA is that this is the short version of our achievements this year!

Lobbying Update

Well done to the DUP and to our lobbying parents. Robin Newton, Iris Robinson, and Peter Robinson all have registered their support for the Autism Manifesto.

It's not too late to encourage your local MLA to register his/her support for the Autism Manifesto.

Full details of how to do this on our webpage: www.autismni.org/lobbying.

HURRY! HURRY!

NOW TAKING BOOKINGS FOR THE FOLLOWING COURSES

Parent Discussion Workshop	1, 8, 15, 22, 29 Sept & 6 Oct 04
Autism & You Parent Training	6 Sept 04 or 11 Oct 04
ASD & Employment Issues	7 Sept 04
Living With Special Kids	9 & 10 Sept
Transition from Primary to Secondary Education	13 Sept 04
Asperger's Syndrome & Mental Health	14 Sept 04 or 5 Oct 04
Use of Assessment Schedules (PEP-R)	20 or 27 Sept, 8 or 18 Oct 04
Fundamentals of Asperger's Syndrome	21 Sept 04 or 12 Oct 04
Fundamentals of Autism	23 Sept 04 or 21 Oct 04
Process of Diagnosis/Assessment & Screening	28 Sept 04
Principles of TEACCH – An Introduction	30 Sept or 14 Oct 04
A Multi-Element Applied Behavioural Analysis Approach to Managing Behaviour	19 Oct 04

For further information

please contact: Gillian Henderson
Admin Project Officer Training
PAPA Training & Resource Centre
DONARD
Knockbracken Healthcare Park
Saintfield Road
Belfast BT8 8BH

Tel 028 90401729

Fax 028 90403467

Email gillian@autismni.org

Website www.autismni.org

*Final opportunity to book your
place on five-day TEACCH*

Training For Parents

15th November –

19th November

WENDY LAWSON

Host Wendy Lawson

"I didn't talk until I was four and I didn't read until I was nine. But I now have two degrees and I am studying for a PHD in psychology," says Australian Wendy Lawson who has autistic spectrum disorder. This disorder affects over 535,000 people in the UK today who struggle with social relationships, communication and imagination.

An international speaker in the world of autism and the author of four books on the subject, Wendy Lawson is the mother of four grown-up children. But like many people on the autistic spectrum, she has obsessions. "Many young autistic children are obsessed by Thomas the Tank Engine. I'm obsessed with piston engines and birds," she proudly boasts.

Wendy was the special guest speaker at the Armagh/Dungannon autism support group meeting on Wednesday 12th May at Dungannon's Sperrinview Special School. Over 80 parents, teachers and health professionals listened to Wendy's insight into the differences between life on and off the autistic spectrum.

"Imagine you are a torch. For those not on the autistic spectrum, you are a torch with a 'wide' beam and can take in lots of information through many senses. But for us on the autistic spectrum, we are a torch with a 'narrow' beam and can only process information through one sense at a time."

Wendy's articulate and entertaining presentation gave hope to parents and professionals alike but she concluded with a clear message to teachers.

"If you are teaching a blind child, you adapt the classroom to help them manage. Children with autism need their environment adapted as well. Take down the multi-coloured artwork from the walls and make your classrooms a calmer environment for your autistic children."



Wendy also featured in PAPA Lisburn's Autism awareness activities.

She spoke to over 300 Parents and Professionals on Thursday 13th May at Parkview Special School, Lisburn.

Wendy's autobiography "Life Behind Glass" is for sale at the PAPA bookshop.

SEATBELTS FOR DISABLED PEOPLE
www.cvelling.com

PAPA Central will have a limited supply of
Safety Harnesses for hire.

Contact Central for further details.

branches

SOUTH BELFAST

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

WEST BELFAST

Contact PAPA Central

DERRY

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

DUNGANNON

1st Wednesday Each Month
Sperrinview Special School
Dungannon 8.00 pm

NEWRY & MOURNE

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

EAST ANTRIM

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

DONEGAL

2nd Monday Each Month 8.00 pm
Contact Fiona for details

FERMANAGH

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

NORTH DOWN & ARDS

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

OMAGH 2nd Wednesday 8.00 pm
Each Month - Gortmore House, Omagh

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

CRAIGAVON/BANBRIDGE

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

DOWN

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

LISBURN

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

NORTH COAST

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

GWEEDORE

Quarterly - An Chuaire
Contact Fiona for details

staff

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

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

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

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

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

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

Kathryn Gillespie, Office Assistant: based at Central Office

Florence Trotter, Early Intervention Therapist: based at Central Office

Irene Anderson, Clerical Officer: based at Central Office, Monday - Friday 9.00 - 1.00

Emer Hamill, Clerical Assistant: based at Central Office, Monday - Friday 9.00 - 5.00

offices

Head Office

Donard House
Knockbracken Healthcare Park
Saintfield Road
Belfast BT8 8BH
Tel: 028 90 401729
Fax: 028 90 403467

e-mail: info@autismni.org
arlene@autismni.org
fiona@autismni.org
janette@autismni.org
jackie@autismni.org
sue@autismni.org
gillian@autismni.org
florence@autismni.org

Website: www.autismni.org

more information

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

disclaimer

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

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