

# ARGH

Autism Rights Group Highland

Spring 2008

ARGH's main focus is group advocacy for adults living in the Highland region. For more information on membership and meeting details please email:

[kb@arghighland.co.uk](mailto:kb@arghighland.co.uk)

Welcome to the argh spring newsletter. We have been very busy at argh during the last months. As many of you may know the Scottish Society for Autism Inverness branch which covered the Highland Region closed last year. Currently the Highland Council is planning a service for children and adults that it is hoped will go some way to filling the gap left by the SSA. ARGH along with other groups has been in consultation with the Highland Council / NHS Highland concerning the set up of this new provision. Currently the proposals for this new service are sketchy. A final report with recommendations will be completed and will need to be agreed and costed before being formally signed off by the Housing and Social Work Committee. It is envisaged that the process will take at least six months. Bill Cook Project Manager (Mental Health and Learning Disability) has agreed to keep us updated on any developments and we will pass on that information **to members as soon as we have it.**

## What is ARGH?

**ARGH is a group run by and for autistic adults. ARGH members are all people who have, or may have, an Autistic spectrum condition.**

**Membership is currently free (but donations are welcome).**

**ARGH meets on the 3rd Thursday of every month from 7pm until 9.15pm. Meetings are only open to members except by agreement of the committee. You do not have to attend meetings if you are a member.**

**ARGH has a commitment to:**

- Inform service providers about what autistic people really experience.**
- Campaign for better services for autistic people in the highlands.**
- Challenge stigma and discrimination through education about autistic strengths.**

# The National Autistic Society Scotland

The Inverness branch now consists of:

Lisa Sturgess, Regional Officer, North West Scotland

Phyllis McWhirr, Social Development and Supported Employment  
Practitioner

Karen Mulvey, Help Programme Officer

Dawn Edwards Administration Officer

The team continues to raise awareness of autism spectrum disorders and will be focusing on the wider community services. Supporting families and professionals is also a high priority and we are happy to take enquiries. We are keen to see the development of a number of Parent Branches across the North West of Scotland to help reduce social isolation and family stress.

We will be holding a number of parent seminars across the North West of Scotland this year; topics include ways in which to help your son/daughter understand that they have an ASD. We will also be running similar training events for professionals.

Service development is also on the agenda and we will be mapping all autism services and resources on our NAS Autism Service Directory.

All enquiries contact: 01463 258802

Dawn.Edwards@nas.org

## **NAS Welfare Rights Service**

**What benefits am I entitled to?**

**How do I complete my benefit claim form?**

**How can I appeal against an entitlement decision?**

**Call the NAS helpline on 0845 0704004 to book a telephone appointment with their welfare rights advisor :**

**Monday to Friday 10am-4pm**

**Or email your query to: [welfarerights@nas.org.uk](mailto:welfarerights@nas.org.uk)**

## **ASD Awareness Training for Staff in Primary and Secondary schools**

During an In-service Day in June, run by the Highland Autism Spectrum Education Network (=HASEN), many of the present staff working with children and young people with ASD in schools were interested to hear about the proposal of ARGH to "train service providers to understand what autistic people really experience". In other words, they welcomed the chance to learn from people with ASD how to improve the school experience of their pupils.

Being both a Support for Learning teacher and a person with Asperger Syndrome puts me in a unique position. During the summer holidays, I devised a workshop aimed at staff in Primary and Secondary schools (i.e. teachers, LSAs, SALTs, OTs and others) who come in regular contact with pupils with ASD.

The workshop is taking the form of direct presentation, creative visualisation, group discussions and time for questions and will last approximately 75 minutes. A fellow member of ARGH and myself have run this workshop for the first time in November for support staff from schools of the Millburn cluster. The feedback was excellent and we hope it has raised empathy for pupils with ASD and by doing so will enhance the relationship between them and those who are working with them in schools.

At the end of January I ran the workshop in adapted form for lecturers in education at Aberdeen University, and teachers from various schools in Highland have also shown an interest in it.

### **Making ARGH known**

To spread the news about the formation of ARGH, I wrote articles about its "birth" and intentions for the newsletter of the Highland Users Group (HUG) and the Scottish Autism Forum. To the latter, I also contributed other articles concerning my personal experience of ASD and information for teachers and mental health professionals.

When my psychiatrist at New Craigs Hospital proposed a research project involving people with Asperger Syndrome, I volunteered to take part in it as well as to help recruit more subjects. This is still ongoing at the time of writing, and I have meanwhile been made research assistant.

My role as the treasurer of ARGH seems to be a minor one at the moment compared to the above projects. Elkie Kammer.

# SAYLIG NEWS

FROM RONA

The SAYLIG is the Same As You Local Implementation Group. There are three operating at the moment in Inverness, Fort William and Aviemore. They were set up after the Same As You document published its 29 recommendations for people who planned and provided services for people with a learning disability and/or autism. It covers voluntary and community services like leisure too. There was a Change Fund set up in each region to help these services become more inclusive and open to people with a learning disability and /or autism. The word Expert\* (a person with a learning disability and/or autism) gets used sometimes when promoting the fact that Experts are involved in delivering awareness. Now for a couple of resource items that were brought to the SAYLIG's notice to share.....

**e-mail [Karen@thecbf.org.uk](mailto:Karen@thecbf.org.uk) for a special newsletter that is coming out for Experts and their carers on 'Planning for the Future' to help those with what is called 'challenging' communication behaviours. We do not really like the term challenging behaviour because there is always a reason that needs a solution but the website is [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)**

**We also found [www.autcom.org](http://www.autcom.org) an autism advocacy organisation dedicated to 'social justice for all citizens with autism'.**

**For an Autism Awareness Calendar to download and print, go to [http://www.treehouse.org.uk/\\_download/HNICJGSM.pdf](http://www.treehouse.org.uk/_download/HNICJGSM.pdf)**

# What it Sometimes Takes

By John Wright

I was watching a TV program on Asperger's Syndrome (AS) – and it made me go “That’s me!” So I found Simon Baron-Cohen’s AQ test on the web and did it, and got a score that said I was well over the threshold for having AS. Not long after that I went to my GP and showed her what I’d done, so she said “Fine, but all I can do is make a reference to New Craigs for a proper assessment.” So we left things at that. Time passed and nothing happened, and eventually I was moved to write to John Thurso, my local MP, complaining about the lack of services for adults in the local area. He replied to me that he had been in touch with Garry Coutts, the head of the NHS in the Highlands, who said I would be “dealt with” in 9 months.

9 months came and went and nothing happened, so I went to my GP again and we went on a campaign of trying to get an assessment somewhere – anywhere! Everywhere we tried either said “our waiting list is so long we can’t accept your reference” or in one case wanted to charge huge amounts of money. Not surprisingly, this one claimed to have no waiting list. But we didn’t have the money and neither did my GP!

Then totally out of the blue came a letter from New Craigs Hospital offering me an assessment. My GP said she knew nothing about this and had written them off, not having received a reply from the first reference. The only thing we could think was that now, some 18 months down the line from that first visit to the GP, that someone had been pressured to activate Garry Coutt’s commitment to John Thurso.

The day of the assessment finally came around and off we went to New Craigs. In the course of a two hour meeting with a senior psychologist there, we gathered that this appointment had as we suspected been arranged in haste to satisfy Garry Coutts rather than my GP. We even established that it was the case that the psychologist lived in England and was doing this assessment on a one off contract.

After this the world changed and we managed to find all sorts of people we’d never known about before, including Argh!

Not long after an article appeared in the Inverness Courier featuring Kerry Brook and Andrew Denovan from Argh!, my first response was to write some comments, which went to the Courier as a letter to the editor. The letter was published in the paper on the 30th October, and was the "Editor's Choice" letter for the week. I think because it made a link between the front page article talking about lack of services for adults in the area, with the front page article the week after which was headed "NHS bosses accused of bullying"

continued over page.....

*I then sent a copy to John Thurso as part of the ongoing correspondence I had had with him, and got a reply. In which he said:*

*"Thank you very much for your letter of 31st October, and for the enclosed article from the Inverness Courier which I had not seen before and which it is very helpful to have".*

I am taking up the matter directly with the Director of Social Work and will write to you further as soon as I have anything of substance to report.

## **FINAL WORD.....**

As many of you will know; we at argh have been asking for some time for a named contact in each area to be available to autistic people who are in need of immediate help. As yet this has not become a reality but we do have a statement from Jonathan King (Head of Operations Community Care):

***"With regard to the wish of ARGH members to have individual named contacts this remains part of our plan, but in the meantime I would like to reassure them that in the current generic community care services all staff are expected to deal with enquiries, including from people with autistic spectrum disorders, without passing the enquirer from pillar to post".***

Below are the community care service contact details; any feedback about how well they are dealing with enquiries would be welcome:

- Inverness (Keppoch Road Culloden) 01520 722541
- East Ross & Cromarty (Castle Street Slioch) 01349 865262
- Skye, Lochalsh & West Ross (Graham House Dornie) 01599 555424
- Skye, Lochalsh & West Ross (Howard Doris Centre, Mill Brae) 01520 722541
- South West Ross (Achtercairn , Gairloch ) 01445 712915
- Skye, Lochalsh & South West Ross ( Old Corry Industrial Estate , Broadford ) 01471 820174