



Autism Rights Group Highland

## Spring 2009

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, a particular welcome to our new members. Thank you to all those that have contributed to the newsletter this time; I'm hoping that more people will be sending a contribution along for inclusion in our next edition. Please send anything you wish to see included to the one of the addresses on the left.

We'd also like to hear from people interested in joining the committee and we're always keen to see people at our meetings ; just ask for more information.

In 2009 I'd like to see us becoming involved in more local issues; maybe you have ideas about what you'd like to see us doing; come along to a meeting or get in touch to share your ideas.

## 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.

## What is going on?

Over the last year we have tried to make sure our members know about some of the things that decide what our local services looks like. Also how we can all put our views and suggestions forward and who to. These things come in the shape of documents mostly and can be very invisible to most service users and their families, if they need someone close to advise.

What a lot of people don't know is there is a duty for services to firstly involve us in our own care and planning and secondly to help shape the services to improve care to others like us and thirdly to involve us to help improve any part of service, NHS or Council that we take or grow a special interest in.

So that could mean a person should be able to ask for the health service they get to include sensory issues if they have been ignored before or to include a contact for times of crisis.

A person then could be a member of a condition specific group to lobby for a service where there is none or to join something like HHVN to work on a research group around disability access to include language or colour tones to an area or to include autism issues on being taken into a ward.

At a third level a person can become an 'asd expert' lay member on groups that run the wider NHS or community care services.

For instance did you know the NHS NSS are the hidden board behind the whole NHS for Scotland and are looking for people interested to help them improve everything from blood collection to buying for hidden patient groups – where do those rubber gloves come from and how do staff know if you are allergic to them? Who puts gluten free recipes on the hospital menus or cafes?

for our Councils duties come in documents, some of which we have mentioned before like PIP-partnership in practice, HAP-health action plan, Autism Pathway, Care 21 (carers with autism should be included) and the Highland Community Care Plan is being written as we speak and then there are the measures but more of them later.

The PIP has a section on asd services but asd does pop up in other places in the document and it has been pointed out in some parts it should be but is not by this group. And highlights one reason why being involved and knowing who to contact is important. Some of the subjects the PIP covers are respite, employment, assessments, advocacy and information.

The HAP is more IQ access related but has two lines in it that recognises that asd is not only about IQ access to good health care and has opened the door to highlight inequalities and discrimination; where patients with hidden needs can help access good health screening and through documents like the access to NHS services, changing the environment or communication around help to access screening or general health care.

The Autism Pathway is a document which is probably due for review now, around the systems available from early diagnosis to care and the professionals and departments that can be involved along the way. With Transitions being the buzz word this should mean a tie up of care after 16+ and 18+ and now that social work services have changed the age range of their teams, NHS and Council should cover transition 23+. And what of the adult asd pathway – well ‘young adult teams now go up to age 65 and we were able to input to the Simon Webster consultations on services needed and the Bill Cook/JPS consultations on what people were needed in the teams – the first four workers will be in place in April – so you as ‘asd experts’ should be asked to review the service, job specs and future of this service.

Now I have mentioned that a Community Care Plan is being written and I have mentioned measures – Outcome Measures in fact which really should be defined by us before the plan is written otherwise this could be another plan where there is a asd section but needs us to highlight that people with asd do not just appear in a silo, in some department next to a shelf marked autism. We appear and more importantly do not appear in every department and community service. People should look for us and if not then you have the right to say ‘I am here’, this is not good for me and this is how I suggest you can make services fit me.

The Outcome Measures are what Government and planners think their services need to do and their view of what a good service would feel like for us ..... but without asking us ..... so that at the moment there are several sets of outcomes measures and they have decided to rework them with people like us .... they are confused, we will be! .... but we hope in this group you will be willing to help tell the planners what your good service experience would be.

To view the PIP [www.highlandcouncil.gov.uk](http://www.highlandcouncil.gov.uk)

For a copy of the HAP [bill.cook@highland.gov.uk](mailto:bill.cook@highland.gov.uk)

To join HHVN [Karen.burnett@hnb.scot.nhs.uk](mailto:Karen.burnett@hnb.scot.nhs.uk)

To input to the HCCP [ian.thomson@highland.gov.uk](mailto:ian.thomson@highland.gov.uk)

To view Care21 [www.scotland.gov.uk/Publications/2007](http://www.scotland.gov.uk/Publications/2007)

## Contribution from Mark W Norton, Secretary, ARGH!

In addition to my duties as Secretary for ARGH!, I am also the Convener of a voluntary railway user lobby group, called the Dornoch Rail Link Action Group, based in the North of Scotland. Our Group was set up in December 2006 to press for major strategic upgrades to the Inverness – Wick railway line, with the Dornoch Rail Link as one main aim.

Why? Our line needs a major upgrade to help it, and the area it serves, to develop properly. The Dornoch scheme is proven to save 45 minutes off the current journey times between Thurso/ Wick and Inverness. Professional studies we have had conducted have proved this to be a big benefit for development of Caithness and Sutherland, particularly with the value of rail increasing greatly in the face of worsening road congestion, high fuel prices and the need to reduce CO2 emissions. To show the case in point, the road journey times between Thurso/ Wick and Inverness take 2 hours 15 minutes. This compares with up to 3 hrs 45 minutes by train to Thurso and 4 hours 15 minutes to Wick! In our time challenged society, it's a miracle that Thurso is still a busy station, with Wick not far behind.

In addition to our campaigning work, I take a great interest in trains in general, both modern and old, as seen in the photographs. Yes, I have driven a diesel railway locomotive – honest! The one shown here was used in the 1930s to haul peat wagons at about 2 mph in Somerset, and is located at the Washford Station museum on the West Somerset railway. Driving this machine is part of the £2 package paid to look around the museum, and contributes to a fun day. In addition, you can have great fun enjoying the train rides of yesteryear in old fashioned carriages behind lovingly restored steam locomotives, or heritage diesels, whichever is your preference. Even these days, there is still lots to be said for train travel.



The joys of steam travel at Stogumber, West Somerset Railway, July 2006



How to drive a diesel loco (it is one, honest!), Washford, West Somerset Railway, July 2006

## Increasing Noise-pollution

Not too many years ago, it was a pleasure for me to travel by train. I would sit back in my seat and quietly watch the landscape go by, then take out a book and read for a while, in between getting up for a little walk-about or having a chat with other passengers. Not so anymore. These days travelling by train can be such a stressful experience, due to increasing noise-pollution, that on many occasions I prefer to stay at home. Usually there are several walkmans bearing their different sounds into the air, mobile phones competing with each other and laptops and computer games beeping all around. I have tried earplugs and ear-phones to shut the painful noise out, but it seems to penetrate my body through vibrations and not through the ears alone. Thankfully, a few trains now offer a quiet coach for passengers like me, but they are still rare.

Going to town has over the past years developed into a similarly stressful activity for the same reasons. There are first of all the shrieking traffic lights whenever I want to cross a road. Within the shops and shopping malls, an increasing number of audio-visual advertisements make sure that I soon forget what I have come for or cannot concentrate on selecting the right items. Even waiting in the queue at the bank or post office or in the waiting-room at the doctors surgery, I am assailed by pictures and voices from a large-screen television. The robotic voice of self-service-checkouts is usually enough to send me fleeing home. Workplaces, too, are becoming increasingly polluted by electronic noise. Computers, phones and so called background-entertainment are more and more seen as essential, be it in offices, factories, education, health-care or other public services. I have often wondered how other people can function in this constant onslaught of unnatural sounds. How can they filter out what they need to attend to and ignore the rest? And how can this process leave them enough energy not to burn out within a short time?

As for me, our increasingly noise-polluted environment becomes more and more disabling, be it in using public transport and other public facilities, going shopping or coping at my workplace. Any campaign for better living conditions for people with ASD has to deal with these issues if it is intended to make a real difference.

Elkie Kammer.

## Notes from a Funky Blue Smurf: Simon Webster, FBS Advocacy

ARGH's chairperson, Kerry Brook, invited me write this article to let you know what I am now doing. I left Inverness in May 2007 when my post as Autism Development Officer for Highland ended. Now I live in Coatbridge with Sandra and our 5 month old son Joseph, and I provide advocacy to children and young people in need. In practice this is usually advocacy for people with autistic spectrum conditions.

This surprises me, because our service is open to *all* children and young people in need in North Lanarkshire. So why do I usually do advocacy for autistic people? We don't specifically promote our service to children with ASCs or their parents.

The advocacy service that I work for differs from ARGH in several ways: we mostly do 'case work', where we try to ensure that individual children get the public services that they want and need; we usually get requests for advocacy from parents, for their children; and we receive substantial funding through the local council. In these ways we are more like Advocacy Highland than like ARGH.

Usually, we have to work with parents to get the services that their children want and need. Maybe I'm working for so many autistic children just because their parents are more forceful in demanding services? This was suggested to me, but I disagree.

I think that autistic children have a great need advocacy for these reasons:

- Public services are generally not designed to meet the needs of people with autistic spectrum conditions
- People with autistic spectrum conditions have great difficulty in adapting to the social, mental and sensory demands of public services

The structures of public services are strongly influenced by budgets and by political aims. These services – education, health and social services, housing, and others – were set up to provide for vulnerable people, but they were designed to deal with the largest numbers of people possible within the budgets available. The result is big, complicated, confusing systems with rules which are not obvious, practices which are not transparent, and social and sensory demands which cause difficulties for everyone. It should be no surprise that autistic people often need much more help than others to get what they want and need from public services!

Because public services are very large and have developed their practices over a long time, I don't expect that any government action will transform these services and make them 'ASC-friendly' in the immediate future. Advocacy is therefore particularly important for autistic people. Individuals require the type of advocacy that I provide, to deal with the problems that public services cause for them now. Collectively, autistic people require the type of advocacy that ARGH provides so that major changes will happen sooner. If you have suggestions for me on how advocacy should be provided to autistic people, or questions for me on how to develop advocacy services, then please email me: [simon.fbs@btconnect.com](mailto:simon.fbs@btconnect.com)

# Research

By Elkie Kammer

I am currently undertaking a research project in conjunction with Aberdeen University, involving all pupils with ASD in Highland Secondary Schools. The title of the study is:

What helps to prepare children with High Functioning Autism/Asperger Syndrome for the social and emotional demands of mainstream Secondary Schools – Exploring pupils' perceptions.

The sub-questions are as follows:

1. What are the pupils' perceptions of their social and emotional experience of Secondary School?
2. What strategies do they identify as helpful in order to cope with the social and emotional demands at school?

What implications does this have for ASD specific input during the transition process from Primary to Secondary School and beyond?

The first part of this research consisted of a Literature Review, revealing alarming figures of mental health problems amongst young people with ASD, such as one study (Ghaziuddin et al, 1998) stating that 65% of adolescents with Asperger Syndrome had been found suffering from clinical depression. Recent developments in brain studies show a clear link between ASD and mental illness, yet the bio-medical model alone is not enough to explain emotional suffering.

Although understanding and articulating emotions is particularly difficult for people with ASD, my aim was to find out from the young people themselves what their perceptions, coping strategies and hopes for the future were. To this end, I devised a questionnaire with the help of colleagues, ARGH members and pupils with ASD, which was sent to all Highland Secondary Schools at the beginning of January, inviting all pupils with ASD to contribute. Despite various forms of reminders, only 2/3 of schools responded and of those 41 pupils (77%) took part in the survey. I am currently holding follow-up interviews with pupils in four different schools (Inverness, Ross-shire and Lochaber) which allow me to clarify data gathered through the questionnaire and to go into greater detail.

A clear picture is emerging as to the above research questions which, greatly simplified, can be summarized like this:

The three major stressors identified by pupils at school are

- Lots of changes happening at once
- Being picked on or made fun of
- Boredom

Perceived as most helpful are

- An adult in school who understands me
- Having a friend or buddy
- Having a Learning Support Assistant

The most important input in Primary school was identified as

- Learning ways of socializing
- Understanding myself better

The interviews also revealed a need for other pupils and staff to have a better understanding of ASD and a greater tolerance of people's differences.

My next step after the remaining follow-up interviews will be a thorough analysis of the data in order to identify outcomes and recommendations, which I am hoping to disseminate through the Highland Autistic Spectrum Education Network (=HASEN) to teachers and members of other professional groups, like Educational Psychologists, Occupational Therapists and Speech and Language Therapists, who are involved with young people with ASD, as well as to give feedback to the participants of the research.

I am aware of the limitations of this study and of the fact that each person is an individual with unique needs, and yet, apart from gaining my degree (MEd), I hope to make some meaningful contribution to enhance the social and emotional well-being of pupils with ASD.

(Elkie Kammer, Inverness)

## **'Informing the public?**

**We were handed a paper 'informing the public? uk newspaper reporting of autism and Aspergers Syndrome, John W Robertson, Journal of Research in Special Educational Needs – vol 9 – no1 – 2009 12-26.**

**For people interested in media research we thought it could be useful. Given that the paper is on newspaper reporting it spent a lot of time on what is ASD and popular understanding, the writer does this to try to capture the full popular understanding of ASD (to engage the readers) and to explain why there can be mixed messages of ASD in the press coverage.**

**The research papers on ASD he uses will contain their own bias and some created their own media frenzies i.e. the much argued over MMR, ASD numbers.**

**The newspapers he uses have their own political bias and ASD subjects seem to come across as very news worthy items is this because papers know they can sell more copies over the related stories they can print thereafter as each party tries to own the issue or rid themselves of it due to a policy misfit i.e. health, education, DRC.**

**The writer suggests the manifestations of ASD are now used in the media of film and even politics, language either to build viewers up to heart warming crescendo of a near cure for ASD or a way of slating a persons policy or practice without using a swear word!**

**In its review of what ASD is and popular consensus, he notes that research by people with ASD themselves seems to be missing though it has been argued by some that the science field is full of people on the AS Spectrum and it would be against DRC regulations to ask a persons diagnosis and also raise the question 'does a research paper written by a person with ASD then become more biased or factual? or does it bring us back to the film media use of the dream of the perfect ASD, that people with ASD can be cured but must be spoken for and deliberated over by others in fear that the person with ASD could become an expert of themselves in their own field. This would then lock out the many researchers, carers, writers, psychologists and many other diverse earning bodies!**

**The writer brings up a key to apply around press coverage which is useful to use over all media**

**: what is reported/shown/said?**

**: what was ignored? (People with ASD experts here)**

**: what was reported/sown/said first?**

**: what was reported/sown/said last?**

**:what got the most time (this one is difficult because in training, it is usual to concentrate on one aspect but following this key a good presentation, would give equal coverage to all aspects of ASD and not just the usual recognised medical consensus of what ASD has been researched to be without the 'experts' with ASD input.**

**The study was conducted over one year so another bias of course could have been elections, publishing of manifestos, against inoculation numbers and various acts and bills covering health education and regional spending, making it more difficult to see the ASD related subjects missed from the major papers reviewed but slanted differently within the freedoms of the smaller local presses.**

**His code marks are extensive and include the above key and also grading the descriptive language used by each paper around ASD, aggressive or humanistic, pessimistic or inclusive.**

**One bias missed maybe where ever papers are based geographically close to major ASD centres thus stories from the research and ASD centres naturally being put to 'local' national papers so becoming national stories. Also the type of story being raised 'locally publically dependant on whether the 'local' centre was medical based or AAD awareness based.**

**A very interesting paper overall and reaches the conclusion that you need to read all the papers to get one picture though not the whole picture as he says this leaves a lack of clarity of a consensus. So the reader's conclusion is to arm yourself with his useful KQs and read all. And of course ask a person with ASD to get the real picture and facts before basing planning or decisions on what you read!**

# SAYLIG NEWS

FROM RONA

Some people have asked about links to minutes and newsletters from the SAY LIG. We have our minutes and newsletters put on to the Highland Council website but it is also a very interesting website to keep in touch with different policies, consultations and service changes; which of course include or should include ASC-autism spectrum condition.

If you go to [www.highland.gov.uk](http://www.highland.gov.uk) then click on social work then click on learning disability services, you will see there are minutes not only from the SAY LIG but also from the old ASD planning group and a history of where planning is now and a link within to ARGH!

If you go back to the social work link and learning disability link, you will also find policies to down load like the PIP-partnership in practice, Access to Community Care, Advocacy Plans. These documents can help you see if changes being made can include ASC. If you feel they don't then you can send a message to the contacts for those pieces of work, so that they can change things or ask Committees like the Housing and Social Work Committee to change things.

The website also covers roads and other services and at first you might say 'what has that got to do with autism?' but through the SAY LIG conversations on roads and difficulties using them, Simon Webster helped a person with ASC get all the sound levels of the road crossing buttons turned down.

So have a look around and see what you think could make Highland a more ASC friendly place to live in and tell the planners or tell ARGH! and we can tell them for you.

**A link for services information in the is**  
**[www.autismdirectory.org.uk](http://www.autismdirectory.org.uk)**

**which has taken over the PARIS website on autism services.**  
**This lists services throughout the country.**

## What's happening in adult services?

To update you all on the new posts for adult services we mentioned last time Bill Cook (project manager Mental Health and Learning Disability) has told us that four specialist social worker posts have been agreed by the council and are awaiting going into the recruitment process. There is one post for each Younger Adults Team i.e. two in the Inverness, Nairn and Badenoch and Strathspey area and one each in the Caithness, Sutherland and Easter Ross, and Ross, Skye and Lochaber areas. He has said that once there is more news he'll let us know.

## Autism Alert Card for Highland

We are working on an autism alert card that will be designed in collaboration with NHS Highland and Northern Constabulary: it will be a way of alerting people to autism and highlighting our needs. It will also carry (if we wish) a contact name / number of someone to call if we need help. At the moment the idea is in its infancy: the card has had a few false starts over the years but hopefully now that we have kick started the process we will see a finished card before too long. We expect to be in consultation throughout the development of the card and will be contacting members to help us with that shortly. If you have a particular interest in this and feel you have ideas that should be heard now please get in touch : [kb@arghighland.co.uk](mailto:kb@arghighland.co.uk)

To see the sort of thing we're talking about you can look here:

[http://www.glasgow.gov.uk/en/Residents/Care\\_Support/GettingaService/AutismAlertCard.htm](http://www.glasgow.gov.uk/en/Residents/Care_Support/GettingaService/AutismAlertCard.htm)

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## 5<sup>th</sup> Annual Autscope Conference London UK

Autscope is the first event of its kind in Europe. The majority of the organizers, presenters and participants are autistic. The environment, schedule, social expectations and presentations are all designed for autistic people; effort is made to minimise sensory and social stressors.

Autscope is a retreat, educational conference and social gathering, where you can socialise, learn, participate in activities and just be yourself. All activities are optional. Autistic behaviour such as repetitive movements (stimming), obsessions and shutdown are accepted as long as it does not infringe on the rights or safety of others.

Autscope

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