

Report on the ARGH Autism Alert Card

May 2016

Who are we?

ARGH (Autism Rights Group Highland) is a collective advocacy organisation based in Scotland but active across the UK with involvement in international projects. ARGH is run by and for Autistic adults, our membership and management are all Autistic people. We aim to improve the lives of all Autistic people through lobbying, campaigning and education.

ARGH is an organisation that:

- Informs service providers about what Autistic people really experience.
- Campaigns for better services for Autistic people.
- Challenges stigma and discrimination through education about Autistic strengths.

Our first alert card was produced as a members only card. Because of demand from non members we extended the scheme in 2010 to be open to all autistic people regardless of age or geographical location; the youngest card carrier who has declared their age is 4yrs and the eldest 87yrs.

Why are autism alert cards needed?

Autistic people report that they are often misunderstood or placed in situations that can become unnecessarily stressful due to communication difficulties on both sides: a two way problem between themselves and the nonautistic person in the situation. Most difficulties derive from misunderstandings that escalate, either to the point of distress or unnecessary intervention by others.

In our society the chances of people mishearing or not understanding a person struggling to communicate are high, the card provides a visual that is easier to understand, clear and to the point, it provides a break in verbal communication: a visual prompt.

The ARGH autism alert card was made as an aid to communication; it is our intention that it can be used in all parts of the community: shops, libraries, colleges, etc. It is meant to be an all round communication tool; not just to be used with the police, paramedics etc, although it will be useful in those situations

too. When talking is difficult, stressful, or when we need a prop, it will aid our communication. It is a way to communicate a need without alarming or confusing the recipient.

It is designed to be mutually beneficial: to help to the autistic person and the person being presented with it, breaking down communication barriers.

When under stress it is not uncommon for an autistic person to have increased communication difficulties. This will vary between individuals and will change depending upon the environment they are in and the amount of stress they are feeling. A person may lose all verbal communication, may appear to be unable to communicate at all or may simply stumble over words / be difficult to understand. They may appear to be understanding whilst not fully processing what is happening or being communicated to them.

The card allows an autistic person to communicate a need. Of course, we know that each person is an individual: the card is limited as to what it can convey and should be seen as a signal to stop and consider, rather than as a conclusive explanation of each individuals needs.

Even for people who experience these difficulties themselves it can be impossible to predict exactly how we may be affected or behave.

There is an option for an emergency contact number to be used with the consent of the individual carrying the card, to enable appropriate support at times of difficulty.



What is different about the ARGH alert card?

The ARGH autism alert card is a card designed and managed by autistic people for autistic people – people who have the best experience of what they need and how they need it, made by us and for us, which makes it unique. It is available to all autistic people and is already being carried by children (as young as 4). We are the end users so it makes sense we are the developers.

We do not have a database or register of card carriers.

We do not retain card users details. This is an active decision based around the wishes of the majority of autistic people and our belief that autistic people should not be subject to 'control' or monitoring and enjoy the same rights to freedom as other citizens: we and other autistic people globally see this as a human rights issue.

Our card is available to all autistic people, regardless of age or geographical location.

The card comes in two formats: identity first "I am Autistic" shown above and the alternate "I am on the autistic spectrum".

The card does not contain multiple logos or a police badge, this is because we made a decision to keep the card uncluttered and to not link autistic people unnecessarily with the police in the minds of the public. Card carriers report to us that they do not want a police badge on their card; we have had contact from people who have carried other cards with a police badge and received a negative reaction from members of the public: the assumption that they are dangerous or that the police should be called to immediately assist.

Our card is recognised and used across Scotland and beyond, including abroad, we have endorsement and support from Police Scotland.

As we do not keep a register or contact our card carriers unsolicited we do not have user survey data. However carriers of the card often get in touch spontaneously, (included at the end of this report are some comments from card carriers and their families), because these comments are spontaneous and not solicited we can be confident that the sentiment expressed is felt very keenly; to go to the trouble of contacting us unsolicited they must feel the card is meaningful. To date we have received no negative feedback.

Some examples of where people have told us they've used their ARGH card:

Hospitals and GP's

Police stations

With police in the community

Football matches

Airports (including internationally)

Library's

Shops

Nursing homes and with care at home staff

School and college

Workplaces

Admin	ARGH (autism Rights Group Highland)
Launched	January 2010
Cards issued to date and known age range of carriers	850 cards. Carried by people ranging in age from 4 years to 87 years (from their own disclosure, we do not retain this information).
Partners	Independently produced. Endorsed, recommended and supported nationally by Police Scotland, supported and promoted at time of launch by Scottish court system and Procurator Fiscal and Sheriff Principal.
Marketing	Posters, leaflets, word of mouth, has been written about online and in print about globally.
Training	Ongoing relationship with Police Scotland through our position on Community Advisory Group.

What next for alert cards in Scotland?

Training

As there are already a range of alert cards to choose from we believe that the priority is not to spend money on replication and duplication. Whether someone chooses to carry a card, make their own card, verbally tell someone they are autistic is their choice, it is the reaction and appropriate action of the person that they tell which we feel needs to be improved: training and acceptance of autistic differences. There is a real need for training from both sides to increase awareness from inside the autistic community and the police / other community members (often it is police that are prioritised which can send out the wrong messages and ignores day-to-day experiences of autistic people).

Rejection of databases: Focus on autonomy and communication, not restriction or control.

This is something that ARGH and many other autistic people across Scotland and globally feel very strongly about: equal access to society and equal citizenship should not require registration or tighter controls than those imposed upon autistic individuals. We do not want an ID card for autistic people, even

a voluntary register will cause problems for our community due to expectations of registration and questions around why people aren't registered: a two tier approach is not useful.

Some statements received in support of our card:

Dr Dinah Murray:

"ARGH in the Highlands have taken up the brilliant idea of an autism alert card, by autistic people for autistic people. Their pioneering card slips into a wallet, grabs attention fast if needed and can prevent situations escalating from misunderstanding and miscommunication."

Dr Wenn Lawson:

"It's the best alert card I've seen: really clean and uncluttered - I like it".

Inspector Ewan Henderson, N Divisions - safer communities, Police Scotland:

"The ARGH autism alert card is a very useful initiative and is a simple and effective way for Autistic people to communicate and share information on their own terms. From a policing perspective, the early introduction of the card will help us improve understanding in order to offer an autistic person a more complete service".

Testimony from some of the people who have contacted us about the card:

Autistic person:

"I think because they mention becoming non-verbal they will be of more use to me."

Parent:

"Just thought I'd let you know I received the autism cards today. They are perfect and just what we needed. Thanks a million."

Autistic person:

"The wording is perfect, I read it and thought, 'that's me' other cards haven't made me feel that way"

Parent:

"This is ideal; it sums up my son exactly".

Autistic person:

“Even just having it in my pocket makes me feel better, more confident. Even when I don’t need it, it’s always there, in case”.

"I got into a bit of difficulty and I was able to present the card at my local police station. They were happy to help. Fortunately no complaint had been made but I was relieved to have a card I could show and they took me seriously. So thanks for producing a useful card that helps to make me feel more confident".