

Report on Autism Alert Cards

May 2013

Overview

Autism is a serious, lifelong and disabling condition affecting approximately 1 in 100 people. Around 50,000 people across Scotland are estimated to be on the 'autism spectrum' which includes Asperger syndrome.

Autism affects how someone communicates and relates to other people, and it affects how they make sense of the world around them. People with autism have varying difficulties with social interaction, social communication and social imagination. They may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells lights or colour.

Autism is a spectrum condition and people with the condition will share the same difficulties but be affected in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of support. Asperger syndrome is a form of autism where there may be fewer problems with speech but difficulties with understanding and processing language. People with Asperger syndrome do not usually have learning disabilities but may have specific learning difficulties, including dyslexia.

Autism is often referred to as a 'hidden disability' as it is not always apparent to people including those in the emergency services that they have encountered someone who has particular needs. Unusual behaviours may also attract attention, for example when experiencing stressful situations, and these need to be properly understood.

People with autism are likely to come into contact with the emergency services, especially those with high-functioning autism or Asperger syndrome as they are most likely to be living with a greater degree of independence than those with severe learning difficulties.

As people with autism often have difficulties understanding the implications of their actions, the motivation of others and coping well in stressful situations, Autism Alert Cards have been developed to improve interactions and outcomes with members of the emergency services and others.

Voluntary Alert Card schemes, for example that provided by the National Autistic Society, have been available for a number of years for people with autism to use. A partnership between the former Strathclyde Police service, Glasgow City Council, Glasgow & Clyde Health Board and autism organisations developed a more focused, local scheme in 2007 which incorporated not only a card but also training for police officers.



Strathclyde Autism Alert Card

The success of the scheme has since been replicated in Edinburgh & Lothian's, Central Scotland, Grampian and Highlands & Islands all based on former police force areas.

In April 2013 the new combined Police Scotland service came into being. This has prompted calls for a review of the existing Autism Alert Card schemes as the former police forces were key partners in the development of each scheme. Mark McDonald MSP lodged a Parliamentary motion on 12th November 2012 on the launch of the Grampian Autism Alert Card which led to a Members Debate on 12th December 2012. Shona Robison MSP responded to the debate on behalf of the Scottish Government and agreed the Scottish Government would take forward Mark McDonald's proposal to look at the potential of the alert card scheme in light of the development of a new single police force.

This report, prepared with the involvement of the autism organisations administering the schemes, aims to help inform that discussion and to identify the most important issues around taking forward the Alert Card schemes between the partner agencies and importantly collects and reflects the views of those who are using the Autism Alert Cards and what their needs are.

Scottish Strategy for Autism

The Scottish Government and Cosla (Convention of Scottish Local Authorities) launched the Scottish Strategy for Autism in November 2011. The development of Autism Alert Cards is not connected to the Strategy but meets its aspirations and contributes to –

Recommendation 11 – that consideration is given to the specific supports needed for the more able individuals with ASD.

Scottish Government Outcomes

Autism Alert Card schemes contribute to the national outcomes framework achieving safer and stronger communities. Safer and Stronger outcomes focus on –

- Living lives safe from crime, disorder and danger
- Live in well-designed, sustainable places where we are able to access the amenities and services we need
- Strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others

The measures for these outcomes include -

- Reduce crime victimisation rates
- Improve people's perceptions of their neighbourhood
- Improve people's perceptions of the crime rate in their area

Summary of current Autism Alert Card schemes

	Strathclyde	Edinburgh & Lothian	Grampian	Central	Highlands & Islands
Admin	Autism Resource Centre	Autism Initiatives	Grampian One Stop Shop	Scottish Autism	NAS Scotland
Launched	October 2007	January 2012	January 2013	April 2012	August 2011 (Highlands) June 2012 (Islands)
No cards issued	830	187	32	100	201
Partners	Police, NHS, Scottish Autism, NAS, Glasgow City Council	Police, NASS, Autism Initiatives, Scottish Autism	NASS, Grampian Autistic Society, Autism Initiatives, Local Authorities, Police, G4S, Health Board	Police, Scottish Autism	Fire & Rescue, Police, Health Board, Local Authorities, NASS
Marketing	Information available on Glasgow City Council website	Local press coverage, considering marketing campaign	400 posters, local media coverage	Posters and flyers to local services and facilities	Posters to local services and facilities, press coverage Alert Card DVD
Training	Police E-learning film on training intranet, autism awareness sessions	Included in police training	Police E-learning module	Police organised awareness leaflets to all staff	

User Survey

We used the 'Survey Monkey' service to survey current holders of Autism Alert Cards across all 5 schemes. In total 80 people out of 1350 card holders (6%) responded to the survey during March and April 2013. Not every card holder could be contacted because the schemes do not hold consistent contact information. The Grampian area was not covered by the survey as their Alert Card was only launched in 2013 and reliable data on use was unlikely to be available.

Results

Are you		
Answer Options	Response Percent	Response Count
Male	67.1%	53
Female	32.9%	26
<i>answered question</i>		79
<i>skipped question</i>		1

Your age		
Answer Options	Response Percent	Response Count
Under 16 years	17.7%	14
16-25 years	44.3%	35
26-35 years	12.7%	10
36-45 years	7.6%	6
46-55 years	12.7%	10
56-64 years	3.8%	3
Over 65 years	1.3%	1
<i>answered question</i>		79
<i>skipped question</i>		1

Which Autism Alert Card scheme are you a member of?

Answer Options	Response Percent	Response Count
Strathclyde	3.8%	3
Edinburgh and Lothian	58.2%	46
Highland and Islands	24.1%	19
Central	12.7%	10
Don't Know	1.3%	1
<i>answered question</i>		79
<i>skipped question</i>		1

How often have you used your Autism Alert Card?

Answer Options	Response Percent	Response Count
Never	60.5%	46
Up to 5 times	28.9%	22
Up to 10 times	6.6%	5
Up to 15 times	0.0%	0
Up to 20 times	0.0%	0
More than 20 times	3.9%	3
<i>answered question</i>		76
<i>skipped question</i>		4

**If you have used your Autism Alert Card, in what type of situations has it been used?
(Please select all that apply)**

Answer Options	Response Percent	Response Count
Police situation	24.1%	7
Health situation	31.0%	9
Emergency situation	10.3%	3
General public situation	79.3%	23
<i>answered question</i>		29
<i>skipped question</i>		51

If you have used your Autism Alert Card, would you say it has helped you:

Answer Options	Response Percent	Response Count
Always	52.9%	18
Sometimes	29.4%	10
Never	5.9%	2
Don't Know	11.8%	4
<i>answered question</i>		34
<i>skipped question</i>		46

If you have had to use your Autism Alert Card, can you tell us about one of the times you used the card?

Answer Options	Response Count
	27
<i>answered question</i>	27
<i>skipped question</i>	53

General Use

out and about - but knowledge of using the card if becoming lost is good.

Uses card on buses and in public play areas. Please about using it and increases confidence.

Less stressful as it avoids the stress of explaining.

just in general public situations

Used it in a shop because I was trying to explain something and I wasn't being understood very well. Showed it to my auntie as it helped her understand the emotions that I was going through

when I have met new people

My son became very high aggressive in a shop other members of public started to interfere which made him worse I ended up having to put myself between them and my son shouting at them and holding the card

I was in a place where there were a lot of people and I got upset and tried to explain why I was scared. I then used the card to show a security person.

To let a person know I was autistic

I have used my card in crowds and other situations which cause anxiety.

When separated from carer whilst shopping

To raise awareness !

My mam uses it if we are out in town and are stopped by people trying to get you to sign up to their charity. As most will not take no for an answer and I cannot cope with waiting for long periods of time, sometimes she just explains why we cannot wait.

general awareness and at airports

my mum keeps it and if needed when I am having one of my moments will show it so the other person involved knows why I am behaving the way I am whether it is crying for what someone else sees as minor or frustrated at things not going as it should without having to explain in

front of other people who have no need to know about my autism.

When we were at the cinema and I was scared we showed the lady my card and she got us out and our money back

I have used it in the bank when dealing with staff. I find official style business hard.

Police

There was only 1 time previous to me acquiring the card when it would have been useful which was when I was stopped by police on my way home and they were looking for someone who looked like my description.

I have used it once when I was anxious and panicky and when I had no phone or money to call autism initiatives/number in hill st edinburgh I showed my card to the officer in the police station. I carry it everywhere a great scheme piece of mind even if I am outside the lothians I was wrongly accused of shoplifting and the police were called to the store. They found my alert card and phoned my sister. She was able to explain what may have happened and the misunderstanding was cleared.

I had to report a crime

I had to give evidence to the police

I have had emergency admissions to A&E on a number of occasions

I have had difficulties with public transport staff and buying tickets etc.

Health

When I had to attend hospital so my carer could stay with me while I was being treated.

Reporting to a police station dangerous actions by a bullying bus driver. To prevent impatience as I clarified my purpose.

health in hospitals

at a+e dept FVR Hospital prior to my admission

I had broken my arm and had long wait things started to move a little quicker once used as I was a little stressed and becoming very restless.

Rather than explaining to a new doctor on an emergency call, showed him the card

How often do you carry your Autism Alert Card with you?		
Answer Options	Response Percent	Response Count
Always	86.7%	65
Occasionally	9.3%	7
Never	4.0%	3
<i>answered question</i>		75
<i>skipped question</i>		5

How does having an Autism Alert Card make you feel when you go out? (Please select all that apply)		
Answer Options	Response Percent	Response Count
I feel safer	46.4%	32
It improves my confidence	42.0%	29
I worry less	37.7%	26
It doesn't make any difference to how I feel	15.9%	11
Other (please specify)		8
<i>answered question</i>		69
<i>skipped question</i>		11

My mum feels safer me having it
 Mother and carers are with my son at all time, we have the mean to explain the reason of potential problems, were they to occur. The card would not make a difference because of this. The idea is good though and certainly for those who are travelling independently, it may help. Ross hasn't the insight to "feel safer" though we are reassured that he has one because he got into a situation in the last year where the card would have helped him greatly.
 I know I have a way to get out of a situation when anxiety gets to bad.
 I do not go out without my mum at the moment, I got it for the future. Public awareness about the card is essential

it makes my mum & dad more confident about my safety should i need help
 Never out alone so haven't needed card - may change once older
 i personally dont use it on my own but will when i am a bit older as it will explain some of my
 strange behavior/reactions in some situations

Are there any improvements you would like to see happen regarding the Autism Alert Card?	
Answer Options	Response Count
	30
<i>answered question</i>	30
<i>skipped question</i>	50

General Comments

Really happy with the card - basic info but to the point
 More people taking it up.
 This card is great to have. I know my son is safe with it when we are out together
 As a parent of a young man with Autism it makes me feel better that he has this card. He never
 goes out without adult support but in the case of an emergency he knows he has this card.
 I hope the autism alert card continues.

Support for one type of card

Would be really good if there was an international card for carrying abroad, holidays etc.
 It should be issued under the auspices of the new National Police Force. A photograph would
 perhaps be beneficial. contact name ad number printed on card
 Making it a nationwide card will be helpful, as will training all police, health staff, carers and
 council government staff in Autism awareness.
 National card would be great. It is also useful when having to discuss important information
 such as in the bank. As such making it more flexible in aim would be good.
 Dont know if applicable but for other regions in scotland to know about it and other places in the
 uk and if abroad too maybe

Please ensure all authorities are aware of this card and what it means

I have 2 cards as my parents are divorced and I have time with both parents (one for Lothian and borders, and one for Strathclyde) Would be better to have one National card and to have all contacts on it as both mum and Dad have moved recently.

Extending the card

Would be good if the card could show any other medical conditions the person carrying the card has.

one for health and hospitals

I think in situations of panic, aggression towards others and property or bullying, the card will not be sufficient. Ideally, the ASD person could just press a red panic button and receive help. Either by stopping at a particular place (safe place- community paces, shops, etc where people have received a little bit of knowledge about ASD, provide a place to rest, be quiet, have a drink and make a call for someone on their behalf. In collaboration to the police. Such a scheme is running in leicester and it is my understanding that is is very successful. It educates the community on ASD and disability generally and create greater opportunities for inclusion. It has my contact's details on it but not my name. So they might say I found it in the street.

I think it should have my name and the name of my social worker on the card as well better awareness needed with public sector staff could be put on back of NI, passport or Scot card?

maybe a photo on it like your passport

Have my photo on it

Suggestions for improving the quality of the service

That it arrives more quickly. I had a rare major travel to Norway chanced to happen during the time of waiting for my card to come, and a friend in Glasgow with a card says it helps her in airport security.

instead of being a paper based card it would be better to be plastic like a loyalty or bank card to keep it good condition and keep it's authenticity. I laminated mine.

This has been done with the card holder

More awareness with proffessionals

That the cover hasn't got 'autism' on the front

Additional Quotes supplied from Highlands & Islands

"My daughter is always loosing her purse. Now she has an autism alert card the police will understand why she has difficulty collecting her purse from them"

Parent from Orkney:

“When I first got it I didn’t really understand what to do with it and why I had to take it everywhere.

When I went to see the Christmas lights get put on unfortunately it was too busy for me but thankfully there was an uncrowded bit for people with disabilities and I showed the man who let people in there my card and he let me in so I got to stay for all of it without feeling too squished.

The only problem now is if I forget my card I feel really vulnerable and I can’t concentrate until I get home and find the card. Also unfortunately my name rubbed off because I take it everywhere with me but when I was at the Pines I just told somebody and they fixed it for me.

The positives definitely outweigh the negatives (like forgetting it). It has definitely helped me”.

A young person from Inverness.

Discussion

According to information submitted by the administering organisations, 1,350 Autism Alert Cards have been issued across Scotland. The implementation of the schemes is broadly similar but record keeping and administration processes vary. The schemes are also marketing themselves to local communities and are connected with autism awareness and training of staff in the emergency services. Each scheme has also established some form of partnership working and the forms of partnership are broadly similar with local variation.

The survey demonstrates widespread support for the schemes from card holders with examples of them helping in both emergency and general situations where interaction with services or the public has been difficult. Card users report improved confidence from carrying their card and carers have also expressed positive support.

The majority of cards appear to have been issued to people under the age of 25, almost two thirds of the total. Although two thirds of cards are issued to males, it should be noted as significant that a third go to females which given the expected prevalence of autism according to gender is very high. We would suggest this demonstrates the cards are much more likely to be asked for by females on the autism spectrum.

The distribution of responses to the survey was affected by the ability of the administering organisations to contact card holders. As a result we have a very high level of response from Edinburgh & Lothian's and a much lower response rate from the largest scheme, Strathclyde.

Although 60.5% of card holders have never had to use their card, 86.7% always carry it and users report that it is making them feel safer, increases their confidence and reduces their worries.

For those who have had cause to use the card, about 40% of users, 24.1% have used it with the police, 31% with health and 10.3% in other emergency situations. 79.3% of uses have been in other, more general circumstances. Amongst those who have used their card only 5.9% report it has never helped them.

In commenting on improving the card schemes the most common issues raised include:

- creating one recognisable national card that would be recognised across Scotland
- a better quality card that is more durable

- use of more personal information including name and photograph
- improving awareness of professionals so they recognise the card and respond appropriately

The survey demonstrates strong support for Autism Alert Card schemes and strong support for the development of a nationally recognised card. To achieve this consideration would need to be given to:

- Which key partners from the police, health, fire service, local authorities and voluntary sector need to be brought together to support a national card.
- How a national card should be administered, and if this should be done locally or centrally.
- How autism awareness is to be delivered across the new national services for police and fire.
- How a national card could be marketed.

There may be clear advantages to forming a more unified scheme at the ‘front end’ for the card holder but such a move would need to assess if the current schemes could and should be merged. There are also advantages to having local schemes from the point of view of marketing to local communities. A role for Autism One Stop Shops and other resource bases would be desirable with a view to promoting a national scheme locally.

Further consideration could be given to:

- Developing the schemes to provide more information on personal safety for card holders and carers, for example connecting with the Scottish Community Safety Network.

Robert MacBean