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Date: 11th November 2013
Our Ref: JPS/MP

Dear Sir/Madam

Consultation on Highland Response to the Scottish Strategy for Autism

I would like to introduce myself; I am the Chair of the Highland Autism Improvement Group.(HAIG)
This is a group of people interested in improving services for autistic adults in the Highland Council area.

The Group has representation from amongst others NHS Highland, The Highland Council, Autism Initiatives, Autism Rights Group Highland, the National Autistic Society, The Department of Work and Pensions, Carers Groups and links with the Children's Services.

I have attached a diagram of the network of organisations who have been involved so far.

Following the publication of the Scottish Strategy for Autism HAIG drafted a work plan in response to help guide improvement work over the next 2 years of this 10 year strategy.

We would appreciate hearing your thoughts on how we can go about achieving the actions outlined in the work plan. HAIG welcomes views from anyone who is interested in helping to improve services across Highland and also would welcome anyone interested in participating in helping to meet the aims.

In addition to this HAIG are hosting a participation and involvement event on December 6th 2013 in Inverness to allow people to contribute personally.

In the meantime please feel free to circulate the work plan as widely amongst your networks and contacts as you wish.

The address for submitting comments and suggestions is

Highland Autism Improvement Group
c/o Alder House
Cradlehall Business Park
Caulfield Road North
Inverness IV2 5GH

Or jeanpierre.sieczkarek@nhs.net

I look forward to hearing from you.

Yours Sincerely

Jean-Pierre Sieczkarek
Area Manager South

Working with you to make Highland the healthy place to be



Chairman: Garry Coutts
Chief Executive: Dr Roger Gibbins BA MBA PhD

NHS Highland, Assynt House, Beechwood Park, INVERNESS IV2 3HG
Highland NHS Board is the common name of Highland Health Board

21st October 2013

Highland Autism Improvement Group

The Highland Autism Improvement Group recognises that the choice of language and terminology used because of the complex nature of the autistic spectrum gives rise to a range of personal and professional perspectives. Because of this for the purpose of this document we have primarily used the terms 'Autistic Adults' or 'Adults on the autistic spectrum'.

The Highland Autism Improvement Group (HAIG) is committed to enhancing the profile of autistic spectrum conditions, and, critically, to improving the support services provided to autistic adults and their carers. Its aim is to educate and inform both the general public and statutory service professionals, so that Autistic Adults enjoy a better quality of life in the Highland Region.

At present the partners include; - NHS Highland, The Highland Council, Job Centre Plus, ARGH (Autism Rights Group Highland), the National Autistic Society Scotland (NAS), Autism Carers Groups and Autism Initiatives.

The aims of the Highland Autism Improvement Group are to work to:-

- **Build capacity of autism services or support particularly in areas where this does not exist or is of a very limited nature.**
- **Address the needs of all people with Autism groups including carers.**
- **Develop plans for service provision in the future.**

Nationally the views of autistic adults have been sought and reported primarily within the Count Us In: It Pays To Listen (NAS, 2012) and the precursors I Exist (NAS, 2008) and Supporting Adults with Autism, A Good Practice Guide (NAS, 2009). The priorities as expressed by adults within these documents include: assessment of needs; sustained employment; choice and control, challenging discrimination; improving professional knowledge and access to support.

Locally, in March 2011 the Autistic people's organisation ARGH (Autism Rights Group Highland) described some of their needs. To -

- Feel secure, safe and understood.
- Be fulfilled and have a sense of achievement.
- Have relationships and social contact with other people on the autistic spectrum.
- Be valued, have our strengths acknowledged.
- Have somewhere we feel at ease and protected in.
- Feel that we are not broken or wrong or bad.
- Feel valued in society and at work and school.
- Have stability, control and order in our lives.
- Have peace and calm.
- Be accepted for who we are with an understanding that Autism is a way of being not a lifestyle choice.

ARGH also listed what they considered would be useful to them in meeting those needs. They are:-

- We need opportunities to work and to study.
- We need safe places.
- We need places where we can go to and be quiet in. Places that we can retreat to when the pressure of being in a public space is too much to deal with.
- Places where we can recharge before we overload, both at home and when out and about.
- We need environments where we don't have to 'read' other people all the time.
- We need places where we can mix together in a social setting, a 'drop in' for people on the autistic spectrum might be good.
- An advice and support service, where we can get help with problems we don't have the ability to deal with on our own. A service that deals with everything from getting a new carpet to dealing with our neighbours. To having help in getting, for instance, a plumber in to the house, when we can neither make the phone call to get their help or deal with them being in the house if we are alone.
- We can have great difficulty in speaking out and, if we don't have family or friends, dealing with things like insurance tax returns or benefits can feel impossible.
- Early help to deal with small problems can make a huge difference and sometimes it is as simple as getting help with going to the shop when we don't feel we can manage it.
- Sometimes what seem like small things are major things for us. A promise to return a phone call can cause a huge panic if that promise is not kept.
- For people in banks, shops, the welfare system, the health service etc to have an appropriate environment and trained staff to help us and deal with our requests.
- Opportunities to socialise.
- For people to be understanding and accepting of our traits and needs and strengths.
- We often need continuity at work and in the wider community.

The Scottish Strategy for Autism

The Scottish Government launched the Scottish Strategy for Autism in 2010 following extensive consultation with those living with autism, their families and friends, service providers and statutory bodies. The Strategy can be viewed here <http://www.autismstrategyscotland.org.uk/>

Part of the national strategy is a list of ten indicators for best practice in the provision of effective Autism Spectrum Disorder (ASD) services.

Number 1 is to create - ***A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.***

The HAIG has reviewed the national strategy and discussed what they believe should be the initial priorities for improving services for adults on the Autistic Spectrum in Highland. The following represents these priorities, acknowledging that this is a living document and should evolve as local needs and services develop, taking account of feedback as appropriate.

Action 1: Create stakeholder forums and communication frameworks with and for adults on the Autistic Spectrum and their families, to include virtual media, open meetings, formal frameworks and to explore other opportunities to engage as they arise.

Objective: Adults on the Autistic Spectrum and their families are involved in the development of a local Autism Strategy and its implementation plan.

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| <ul style="list-style-type: none">a) Develop and agree a HAIG communication framework that shows the main communication paths and partners/associates.b) Each HAIG member to develop and publish internal communication paths to ensure |
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information is shared in a consistent and verifiable way.
c) HAIG members to hold meetings with their own constituents to develop and pursue ideas/solutions and submit to HAIG for consideration.

Action 2: Establish multi-agency commitment from housing, employment, criminal justice, local authority, NHS and the voluntary sector.

Objective: There is a joint multi-agency vision and joint outcomes within the local autism strategy and implementation plan.

a) Formalise representation at HAIG from statutory agencies and voluntary sector.
b) Formal members to develop action plan on behalf of their agency.
c) Members to provide summary progress reports against identified actions.

Action 3: The development of a multi-agency training plan.

Objective: Adults on the Autistic Spectrum are confident that professionals are skilled and knowledgeable. Adults on the Autistic Spectrum are treated equitably and are free from discrimination. Professionals have access to continued professional development concerning autism practice. General public and professional awareness of autism is raised.

a) Take in to account NES plans to develop training and education for Highland, also ensuring it is based on seeing Autism from the perspective of the Autistic adult.
b) Public Sector Agency partners will nominate Autism link managers to lead on implementing training within their area of responsibility. Consider creation of a training team.
c) Develop HAIG's capacity to produce training written by Autistic professionals/individuals. Identify key professional across Highland with specialist knowledge, skills & experience. Develop standardised/tiered training programme.

Action 4: Remove barriers to accessing services.

Objective: Develop multi-agency 'care pathways' for each life stage including assessment and person centred interventions plans.

a) Develop referral and assessment pathway for primary care.
b) HAIG multi agency partners to develop local standards for supporting adults with Autism.
c) Implement transitions guidance for young people with Autism moving on to adult services care and support.

Action 5: Improve support for Adults on the Autistic Spectrum.

Objective - Build capacity of Autism services or support particularly in areas where this does not exist or is of a limited nature

a) Utilise Autism Mapping Project report to identify service gaps and prioritise areas for development, including joint plan with Children's Services to assess future demand, calculate capacity requirements and manage transitions.
b) Draft action plans for each prioritised area for development.
c) Identify HAIG members to lead implementation of action plans.

Action 6: Improve employment opportunities and support for Adults on the Autistic Spectrum.

Objective - help those with autism find and keep permanent employment

a) Hold special HAIG employment events across Highland and invite appropriate representatives from employability organisations, statutory sector & employers.
b) Ensure advisor support through Dept of Work & Pensions and partner organisations is accessed effectively ensuring maximum job opportunities and job retention.
c) For public sector agencies to become exemplar employers of Autistic adults, offering work placements, work experience, equal opportunities for permanent employment and support for existing employees identified as being on the Autistic Spectrum to remain in employments.

Action 7: Provide easy access to information about autism and services.

Objective: Adults on the Autistic Spectrum, their families, and those who support them formally and informally will have access to information about the condition and services that may support them.

a) Work with NHS Communications Dept to develop an awareness raising strategy.
b) Seek feedback on effectiveness of awareness raising strategy.

c) Make best use of digital technologies to provide information and ensure the information is easy to understand and offered in a variety of formats.

Action 8: Establish a group and process of monitoring and evaluating outcomes (both personal outcomes for autistic individuals and outcomes of the implementation plan) using suitable measurements and data gathering techniques; use this to inform progress and evolve the 10 year strategy.
Objective: Improvements in services are monitored and reported upon.

- a) Adopt national outcome measures (on publication).
- b) Develop monitoring process.
- c) Prepare annual report on progress against national outcomes to Adult Health and Social Care Commissioning Group.

Action 9: Make a commitment to the promotion of advocacy and access to advocacy for all Autistic Adults including people who are seldom heard, e.g people living in very supported environments or people who others struggle to communicate with. Include: self advocacy, independent advocacy and collective advocacy.
Objective: All Autistic Adults have easy and genuine access to advocacy.

- a) Develop plan for the implementation of a collective advocacy service.
- b) Develop a plan for the implementation of self advocacy.
- c) Develop partnership with advocacy organisations to improve access to independent advocacy for Adults on the Autistic Spectrum.

