

Adult Autism in Sheffield: A Communication and Engagement Strategy

Background

People with autism spectrum conditions (ASC) are all individual and different. But to a greater or lesser extent they all experience difficulties of communication: the expression of their own thoughts, ideas, feelings, wishes and so on; and the understanding of other people's words, behaviour, thoughts and body language. They experience problems in coping with social situations and with many issues that arise in everyday life.

These problems are intensified when they are faced with unfamiliar people, places, forms of language, ambiguous meanings and unspoken or hidden rules of behaviour - situations which neurotypical people learn to deal with quite well.

People with ASC conditions are often distressed by too strong or too many sensations and confused by an overload of information. And because autism is often a “hidden” condition the autistic person is regularly confronted by people who do not understand their individual difficulties and know little about autism in general.

All of this means that people on the autistic spectrum struggle to take a full part in society and to fulfil their potential as people and as citizens. They and their families are often isolated from each other and from community services and structures.

It also means that there is a special need for - and a need for special care in designing - communications for the autistic community and a need to create autism-friendly environments⁽¹⁾ to allow autistic people to be included in making decisions that affect them and to participate as fully as possible in all aspects of life.

Need for a communication and engagement strategy

In Sheffield there is a particular need because such services and initiatives as there are for people across the autistic spectrum as a whole are fragmented, uncoordinated and underdeveloped compared to those in many other locations. Nor is information about initiatives, plans, opportunities or services easily accessible for the people who need it. However, information alone is not enough. Given the relatively small number of people, autistic and neurotypical, who are actively involved in Sheffield in discussion and activity around autism, there is an urgent need for many more people at all levels to be included. A conscious strategy of proactive engagement and action must be developed.

Any communication and engagement strategy for autism in Sheffield should include:

1. Autism training of all staff in public-facing roles in the public, private and voluntary sectors, appropriate to their responsibility and specialist areas.
2. Campaigns of autism awareness aimed at the general public that go beyond a simple description of impairments and which seek to promote understanding and empathy or acceptance.
3. The use of as many different channels as possible to engage and involve autistic people themselves and their families and carers, including “difficult to reach” populations such as older people and members of Sheffield's large BME communities.
4. The promotion of opportunities for autistic people, their families and carers to meet, support

each other, socialise, share experiences and information and to participate in the planning and development of their own services, organisations, facilities and forums. This would include their participation in voluntary groups of all kinds as well as in the “official” committees and structures of the City Council and NHS that affect them.

To these ends in Sheffield we need specifically also to:

- develop an effective Autism Partnership Board, with adequate representation of autistic people across the whole ASC spectrum, their families and carers, and involving all relevant stakeholders and partners: service providers, voluntary organisations, professionals, NHS and social care commissioners and others. There should be subgroups that specifically address the issues of training / awareness and communication / engagement, as well as other areas of concern such as identification and diagnosis, assessment and support planning, housing, employment, safeguarding, young persons / education / transition, criminal justice, carers and so on. Special attention⁽¹⁾ will need to be given to facilitate the active participation of autistic members of the board and sub-groups.
- involve autistic people, their families and carers in any other initiatives that are currently planned or ongoing in any of the areas described above;
- develop and proactively maintain a network of autistic people, their families and carers, professionals, concerned individuals and groups to promote the sharing of knowledge, lived experience, personal stories, information and ideas, and to ensure a continued momentum and a supply of people and ideas to drive change and improvements;
- publish and distribute as widely as possible information about, for example, the SAANS service, diagnosis, assessments, health (including mental health) and social care, training, education, opportunities for supported employment and volunteering, local service providers and their offerings, autism and carers' organisations, the employment of personal assistants, brokerage etc;
- with all the above objectives in mind, to develop an autism-specific website, linked for example to the autism partnership board or to a relevant voluntary organisation, to act as a 'one-stop' online hub or information resource for all matters relating to autism / ASC in Sheffield.
- to maintain an autism information and advice centre, open at specific hours in the week in a city-centre location, with paid or volunteer staff available to give 'signposting' and initial advice and information about autism and about relevant services to members of the public.
- In addition, to use social media, exhibitions, leaflets, posters, pamphlets, information points in public libraries, doctors' and dentists' surgeries, public offices, educational institutions etc with the aim of distributing information about autism and services as widely as possible, including where possible the use of translation into minority languages;
- encourage the development of advocacy, befriending, help with financial matters and benefits;
- continue to develop the Sheffield Directory⁽²⁾, the Stratify⁽³⁾ online forum for people with autism, Equality Hub⁽⁴⁾ and other existing local initiatives;
- offer funding and practical help to existing voluntary organisations such as SAPAG, the

Sheffield Autistic Society, their support, social and creative groups and helplines, together with other voluntary organisations and charities who offer help, services and facilities to autistic people, their families and carers, as well as to foster new activities and groupings around autism;

- ensure transparency and access to all public (City Council and local NHS bodies') publications and documents relating to autism – terms of reference, membership, agendas, minutes of meetings, reports etc;
- monitor and oversee official communications, publications and materials in Sheffield to ensure they are easily understood and autism-friendly;
- develop links with Sheffield's two universities and encourage research, talks, events, conferences;
- develop links with schools and colleges for the benefit of young persons in transition to adulthood;
- encourage Sheffield College and other providers to develop courses in such areas as independent living skills, relationships, money management and civic participation;
- create links with employers with the aim of developing employment policies and increasing employment opportunities for people with ASC conditions. Also to ensure that assistance is provided to help autistic people to gain employment and to support them adequately when they are in employment;
- encourage liaison with other local authorities and people / organisations in the Sheffield City Region and beyond. The Greater Manchester Autism Consortium provides a model of what can be achieved when neighbouring authorities work together on the strategic development of local services for people with autism and a common platform for information sharing⁽⁵⁾.
- learn from national, regional and local organisations such as the National Autistic Society⁽⁶⁾, Autism Connect⁽⁷⁾ and from the work and progress made in other local authority areas and regions, such as Greater Manchester⁽⁵⁾, West Midlands⁽⁸⁾ and Lancashire⁽⁹⁾, some of whom are already doing much of the work that is described above.

References:

1 See for example:

<http://www.autism.org.uk/get-involved/tmi.aspx>

<http://www.autism.org.uk/~media/NAS/Documents/Working-with/Social-care/Involving%20people%20with%20autism.ashx>

<http://www.autism.org.uk/~media/NAS/Documents/Working-with/Autism-strategy/It-Involves-Us.ashx>

<http://www.wiltshire.gov.uk/disabilities-ld-doh-autism-poster.pdf>

<http://www.autism.org.uk/~media/NAS/Get-involved/TMI/NAS-TMI-Companies-Guide.ashx>

2 <http://www.sheffielddirectory.org.uk/kb5/sheffield/directory/home.page>

3 <http://stratify.org.uk/>

4 <https://www.sheffield.gov.uk/your-city-council/policy--performance/how-we-will-deliver/other-strategies-plans-and-policies/equality-and-diversity/equality-hub-network.html>

5 <http://www.autismgm.org.uk/index.php>

6 <http://www.autism.org.uk>

7 <https://autism-connect.org.uk/>

8 <http://www.autismwestmidlands.org.uk/>

9 <http://www.autismlancs.org>