

Think autism

Examples of how local councils support people with autistic spectrum conditions to live fulfilling lives within their local communities

Introduction

There is a great opportunity, and challenge, for councils and councillors to use their unique local leadership role to drive continued improvements in the delivery of services and support for people with autism – and ensuring that these services and support are developed with people with autism, and not just delivered to them.

Many local areas are engaged in innovative work to promote the participation and engagement of people living with autistic spectrum conditions (ASC) in their communities and this report highlights a few case studies.

We hope, by bringing these examples together, that other areas may reflect on the positive work that they are involved in with their local partners, and feel a renewed commitment to build on this. This will not necessarily require additional resources – much can be achieved by the creative use and development of effective partnerships with the community and voluntary sector, alongside user-led organisations and through partnership working with business.

We hope that local areas will find this document a helpful contribution to the planning, commissioning and delivering of services for and with people with ASC and their carers.



Councillor Izzi Seccombe

Chair, Community Wellbeing Board, Local Government Association (LGA)

Contents

Background	4
<hr/>	
Case studies	
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An equal part of my local community	6
Bristol: creating an 'autism-friendly' city	6
Surrey: creating a network of autism champions	7
Richmond: a place to meet	8
The right support at the right time during my lifetime	9
Staffordshire: helping with student life	9
Hertfordshire: helping with the transition to adulthood	10
Developing my skills and independence and working to the best of my ability	11
Leicestershire: providing a one-stop-shop	11
Nottinghamshire: looking for creative solutions	12
Walsall: making use of befriending	13
Liverpool: helping with employment	14

Background

In April 2014, the revised strategy on Autism was published, 'Think Autism'. This strategy builds on the original adult autism strategy 'Fulfilling and Rewarding Lives' published in 2010. The revised strategy reaffirmed the five areas of action set out in the Adult Autism Strategy aimed at improving the lives of adults with autism.

Within the original 2010 strategy these included:

- training staff who provide services to adults with autism
- identification and diagnosis of autism in adults, leading to an assessment of needs for relevant services
- the planning and provision of services to people with autism as they move from being children to adults
- local planning and leadership. The strategy sets out that local councils should develop a commissioning plan around services for adults with autism that reflects the output of the Joint Strategic Needs Assessment (JSNA) and other relevant data around prevalence.

The revised 'Think Autism' strategy retains many of the core components as set out in the original strategy in respect of training; identification, diagnosis and assessment of people with autism; the planning and provision of services for those moving to adult services and local planning and leadership. Many of these requirements are also now included within the Care Act and the Children and Families Act 2014.

'Think Autism' builds on these. It includes a new focus on building supportive communities, promoting innovative local ideas and services and improving advice and information for people with autism. It includes a significant shift away from a narrow focus on statutory services to a broader focus on building communities that are more aware of and responsive to the needs of people with autism. It sets out a programme of cross-government actions to support the delivery of this at a local level, including developing a community based 'Think Autism' awareness and champions programme, modelled on creating Dementia Friendly Communities, that many local areas are actively supporting.

In March 2015, the Department of Health published new statutory guidance to support 'Think Autism'. The guidance builds on progress that local councils and their partners have made over the last five years in respect of services for people with autism and sets out expectations for local areas so they can continue to develop services and support in ways that reflect the assessed needs and priorities of their local communities.

Case studies

These case studies have been written by councils for councils, so that the good practice and ideas in one area can be shared with others. They are presented from the council's perspective.

Bristol: creating an 'autism-friendly' city

Creating dementia-friendly cities has proved to be a successful way of encouraging communities to become more accommodating to the needs of people with the condition.

So Bristol City Council has adopted the principle as a way of improving the lives of people with autism.

The council's aim of becoming an 'autism-friendly city' is based on the idea that most people with autism do not want or need formal services, but do require those around them to be accommodating to their needs.

Helen Pitches, the council's Joint Commissioning Manager for Adults, says: "It is about understanding the condition and creating the right environment for people. We have tried to raise awareness about it and translate that into how we deliver services."

"The aim is to help people with autism engage with life in the city. The concept has really worked for dementia so we have tried to create the same momentum with autism."

To help achieve this, the council has been providing training to its staff to help them develop autism-friendly practices.

The content and length of training varies depending on who is taking part. It is being rolled out across different departments, including leisure and housing, with the aim that staff then consider the needs of people with autism in the services they provide.

The push on autism-friendly practices has also led to a number of other initiatives, including a social prescribing pilot project that was run in partnership with two GP practices recently and is currently being evaluated.

Under the scheme, people with the condition were referred to a key worker who provided one-to-one support for people to try to help them get more involved in community life.

This involved activities as broad-ranging as accompanying them to social groups to helping them access local services.

The key worker was linked to the Bristol Autism Advice Service, which runs a drop-in clinic and provides a range of educational and employment support for people with autism.

The council has also set up a work placement scheme. Project Search is run in partnership with City of Bristol College and Sixteen Co-operative Ltd and involves people with learning disabilities, including autism, being able to do full-time paid work.

They are given a mentor and spend time at three different placements for about 10 weeks each. Afterwards they are given continued support in finding future employment.

One recent intern says the placements have made the world of difference. "I've realised the skills I've been learning on Project Search are like the ones I've seen on job adverts. Now I can apply for paid jobs."

An autism forum has also been established to ensure the voice of people with autism is heard at a strategic level. As well as people with the condition, the forum includes key council and NHS staff.

"The forum acts as an important and influential body ensuring the autism strategy is implemented and that we are prioritising it right," says Ms Pitches. "It keeps us on our toes."

Contact:

helen.pitches@bristol.gov.uk

Surrey: creating a network of autism champions

The power of the local community has been harnessed by Surrey County Council to improve the lives of people with autism.

It has done this by creating a network of more than 100 volunteer 'autism champions'

They have been recruited from all walks of life including the Police and Probation Service, employment agencies, local colleges and support living services.

Thomas Moore, Surrey's Autism Commissioning Manager, says: "One of the biggest problems people with autism face is people not understanding the condition. So what we have tried to do is encourage the whole community to learn more about it and how they can shape their services to accommodate the needs of people with autism". "The network was launched in 2005 with the aim of recruiting 50 champions so it has surpassed our expectations."

Over 200 people have been trained. Everyone who volunteers to be an autism champion gets six months of mentoring and training. The mentors are experts in autism from the council's social care team, the local NHS and independent sector support providers.

The training is pretty rigorous. The trainee champions meet with their mentors for half a day once a month and have to complete work between these meetings.

The training materials have been developed with The Tizard Centre, part of Kent University, and the National Autistic Society.

The idea is that once the training has been completed the champions can spread their knowledge across their places of work. "It is not just about making them aware of what they can do, but giving them the skills to encourage others to make a difference too", says Mr Moore. "For example, one of our champions from an employment agency went and spent time with a supermarket manager who employed someone with autism."

The champions also get together yearly at network meetings with the aim of spreading good practice – and it certainly seems to be working.

An evaluation of the champions network overseen by the Tizard Centre has demonstrated the impact it has had. The research found the training had improved understanding of the condition and what approaches could be taken to improve support to those with it.

It also provided qualitative evidence. Eight individual sites were examined, including a day centre, a supported living centre and residential care home. In each case practical changes had been made including the introduction of dedicated quiet areas and more personalised care planning.

The experience of individual champions also shows the effect the scheme has had. Surrey Probation Officer Sarah Cannon, who completed her champion training in 2014, says: "It has really opened our eyes to what can be done. We are seeing increasing numbers of people with an autism spectrum condition in the criminal justice system.

"We are still in the process of making changes, but it is already clear there is much we can do – and many of the steps are relatively straight-forward." She says these include flagging up in advance when there is a change in probation officer or carrying out pre-sentence interviews over two shorter sessions rather than one long one.

"It is about being aware of the challenges people with autism face and making changes to accommodate their needs," she says. "For example, some of our interview rooms are really bright or in areas that are noisy so we are moving people to more appropriate areas when that is necessary."

Contact:
thomas.moore@surreycc.gov.uk

Richmond: a place to meet

Richmond has set up two drop-in groups to help people with autism meet others and become involved in the local community. One group is for younger adults and one for all ages. Each group attracts between 10 and 15 people.

The groups meet fortnightly at a local community centre and provides an opportunity to learn and socialise. Activities have included bowling trips, cinema outings, picnics and barbeques.

There are also structured learning opportunities, such as sessions on how to deal with issues such as confrontation, stress and anxiety management.

Feedback has been extremely positive. One mother of a 40-year-old woman who has taken part wrote to the council recently to praise the impact the group had had on her daughter.

She said: "It is a wonderful group that has become an oasis for her. For the first time she has met people who understand".

The groups are run by Resource for Autism, a north London-based charity, and have been funded through the Better Care Fund.

Rebecca Swist, Richmond's Autism Specialist Worker, says: "We let the people taking part help decide what they do. It is really up to them. It is their group". "These are people who do not fulfil the eligibility criteria for formal help so I think it is important that we have something there for them. It is early days, but feedback has been good. And its not just the social side of it, the group also seems to be reducing demands on primary care and social care."

The mixed-aged group was set up in early 2014, while the younger group, which tends to attract people from aged 18 to 25, was established later in the year after a 12-week pilot of a social skills project.

Called Social Eyes, the idea of that project was to encourage the development of social skills by working on techniques such as starting a conversation, maintaining eye contact and personal space. It was developed with the help of the National Autistic Society.

Ms Swist says: "It was so popular that when it stopped the young people wanted to keep meeting so that is why we set up the second drop-in group and why we do the more structured learning as well as the social side of it. They really wanted to continue. We will probably look to do something similar to Social Eyes again in the future. We also run two support groups for carers that are very popular."

Another local project run by Richmond is called 'Project Search', which combines college placements with work experience at Kingston Hospital, GlaxoSmithKline and the Heathrow-branch of Hilton. Richmond Works, run by Remploy, offers adults of all ages support in getting work through job coaching and training.

Contact:

rebecca.swist@richmond.gov.uk

Staffordshire: helping with student life

Staffordshire County Council has been providing help to people for a long time. Twenty-five years in fact.

ASSIST (Autism and Sensory Support in Staffordshire) provides specialist support to people over the age of 16.

It has a team of 70 staff and focuses its work on helping college and university students, people at work and people in their own home.

The team currently has more than 200 clients on its books. The majority of the autism work is focused on the college and university side of the service.

Among its staff, the team has tutors, communication workers and note-takers who can help students with the condition adjust to university and college life. Mentoring support is also provided.

“We tailor the help to the individual,” says Dave Powers, a translator and transcription coordinator in the ASSIST team. “Some people just want a little bit of help, others need more intensive support.

“For the students it can range from help in lectures and with their work to help settling in and adjusting to life at college and university. “Some pupils may have moved to the area and find it difficult to adjust to life with new flat mates and all the other challenges of in higher education.

“Students who need help are normally identified during the UCAS application and we can then be there to help them from the start of their course.”

One of the students studying interactive media at Stafford College was given help in the class and with his research out of class. In his final year he achieved three merits, enabling him to gain a place at university to continue his studies.

He was full of praise for the help he got from the ASSIST team. “The staff have always been very helpful and easy to get on with. They were focused and help me to organise my time to keep on track getting my assignments in on time. “I feel the support given by ASSIST has helped me to achieve three merits in my final year and this has enabled me to go onto university. Without this help I feel my grades would have only been a pass.”

Alongside supporting students, a large number of clients get help with day-to-day activities in the community.

Mr Powers says: “We help some people when they go shopping or have doctor appointments or legal appointments, while for others we just spend some time helping them with their correspondence, writing letters and making calls. It all depends what they ask for. “We approach it from the point of view that it is best to let them decide how to use the time and budget they have been allocated.”

The ASSIST team also provides employment support through the government’s Access to Work scheme. This can include communication help at job interviews and support finding and applying for jobs as well as support in the workplace when that is needed.

Contact:
assist@staffordshire.gov.uk

Hertfordshire: helping with the transition to adulthood

The transition from child to adult services is often a challenging one, especially for people with autism.

To help ensure this process goes smoothly in Hertfordshire, the county council has a transition coordinator and dedicated young people's social worker in its Asperger's team.

The posts were created as part of a wider revamp of how the council provides support to people with autism.

They were created in April 2013 when the council established an Asperger's team for adults to sit alongside its mental health and learning disability teams.

Nicola Alston, a senior manager in the council's adult care services department who oversees the Asperger team, says: "We set up the Asperger's team because it was becoming clear that people with the condition were falling between learning disability and mental health services.

"But when we did that we wanted to make sure there was support there for young people when they are becoming adults. It is a difficult time as there is a lot changing in terms of school, how they use health services and because they are thinking about what they want to do in the future."

The transition coordinator gets referrals from a variety of sources, including the council's own child social care teams, child and adolescent mental health services and schools. Currently there are 88 young people on the team's books.

"There are a variety of ways we can help," says Eldfrid Becker, the Transition Coordinator. "It is all about working out what is best for the individual. So the first thing we do is ask them about their aspirations. If they are wanting to explore work opportunities we work with our work solutions team to get them work ready.

"Others may want to move out of home so we can work with them to do this or they may be getting direct payments for the first time. It really depends.

"We work alongside schools and colleges in preparation for young people leaving and moving onto the next stage of their lives."

Ms Becker works with young people from the age of 18 to 25 and begins preparing for adulthood from the age of 16.

At the age of 25 they receive help from the wider Asperger's team, which has eight staff. These include the team manager, three social workers, an employment officer, an expert by experience (who themselves has Asperger's syndrome) and two community care officers.

Ms Alston says: "We have received really good feedback since we set up the specialist service. People with Asperger's do not fit the traditional learning disability and mental health services so we have been able to tailor our support, which of course has better outcomes for our clients."

One mother said the help her son received when he started college was vital in helping him settle in. Ms Becker visited the college before he started and met with his learning support and personal tutor and is now staying in close touch with him during his time there.

The mother said she was "extremely grateful" for the help given to her son, adding it had helped ensure his move to college went well.

Contact:

nicola.alston@hertfordshire.gov.uk

Leicestershire: providing a one-stop-shop

A diagnosis of autism or caring for people with ASC can make life complicated. Leicestershire County Council is helping people to cope through its Autism Information Hub.

Set up two years ago, the service effectively acts as a one-stop-shop, helping people where it can or signposting them elsewhere if it cannot.

Laura Clark, the Hub's Manager, says: "We are there for anyone who has a question. It's a 'can I just ask service' I guess. Parents, carers or people with autism, they all come to us.

"We get questions about everything from where to go for a diagnosis to questions about benefits. People just need a bit of help finding there way round the system – and that is where we can help."

The Hub has a telephone line and email enquiry service, but also holds 'clinics' in local libraries. A range of other services are provided too, including training for local employers and advice and CV support for people with the condition who are looking for work.

"Most of the people we deal with are those who are not entitled to formal support," says Ms Clark. "They are high-functioning, but that doesn't mean they don't need help and support along the way."

The council has also set up a dedicated team to help improve the support available to people with autism in other ways.

The autism team seniors – Mark Brooks and Zoe Horton – were appointed in May and July 2013 respectively. Both posts are funded for two years.

There are several strands to the work. One of the core roles is to provide training and support to social care staff who are helping adults in the community with autism.

The team has produced an information pack for social workers and community care assessors to help them understand more about the needs of people with autism.

Mr Brooks and Ms Horton have also organised one-day training sessions run by the National Autistic Society. Over 40 staff have taken part in these so far and there are now plans to roll out this training to more front-line staff throughout the year.

There is also a strategic side to the work the team does. For example, they have worked with the council's market development team and local providers to try to improve the range of services on offer.

Mr Brooks says: "We try to identify gaps in the market and then encourage providers to extend their services. We have done presentations and open dialogues with organisations. It's in everyone's interests to ensure there are the right services in the right places, in order to meet each individual's needs."

Contacts:

laura.clark@nas.org.uk,
mark.brooks@leics.gov.uk
zoe.horton@leics.gov.uk

Nottinghamshire: looking for creative solutions

Nottinghamshire County Council has placed a big emphasis on looking for creative solutions to ensure funding for those with autism stretches as far as possible.

That has meant harnessing the power of new technologies and working with clients to find innovative ways to use their personal budgets.

This has involved everything from paying for cleaners to one-off purchases of equipment.

The council has also looked to use digital technologies, such as texting, to help people with autism.

Since the council's Adults with Asperger's Team was created in 2009 it has seen over 650 referrals.

Team Manager Christopher Mitchell says: "We have put a great deal of effort into maximising personal budgets – whether that is a managed personal budget or a direct payment.

"You have to work out what is best for each individual. Obviously direct payments are the first option, but they are not always for everyone. People with autism do have a greater sense of anxiety so asking them to take responsibility for their care in this way can be quite intimidating. We spend time with them working out what is best for them.

"You have to find out what their special interests are and what help they need to get involved in things they enjoy."

This approach has led to a variety of ways of using an individual's personal budget. For example, one young man used part of this personal budget to buy an electric voice recorder, which provides prompts for up to three months in advance. Although it cost £110 upfront, it reduced his reliance on formal support.

Another client used his personal budget to employ a cleaner as he could not manage to do this himself. It was a five-hour package and led to improved confidence and self-esteem.

Meanwhile, another man used his personal budget for assistance in going out so he could pursue his passion in photography. He has since spent time as a volunteer with the Red Cross.

The approach adopted by Nottinghamshire has not just focused solely on personal budgets.

In the past 18 months the team has piloted a project using a telecare scheme called 'Flo'. This is the text messaging service that is often used as part of packages for older people to remind them to take medication.

John Stronach, one of the two community care officers in the team, says it has had a huge impact on some clients. "There is one man who was always worried he had not locked the doors. He lived with his mother and he kept disturbing her at night. Their relationship was breaking down because of it."

"So we used Flo to send him reminders to lock the doors and then he records it when he has. It has meant that he does not have to get up to check.

"In fact it is working so well that he has started sleeping right through. I don't think he even checks it anymore. Simple solutions like this can make a big difference."

Contact:

christopher.mitchell2@nottscc.gov.uk

Walsall: making use of befriending

Befriending schemes have become popular in recent years as a way of ensuring older people do not become isolated and lonely.

Walsall Council has adapted the concept to help adults with autism. The Walsall Befriending Project is offered free to people with ASC, with the aim of helping them build friendships and aid personal development.

Once a month volunteer befrienders will join the person to do an activity they have expressed an interest in. That can involve anything from going for a walk or shopping to going to the cinema and watching football.

Once a month they are also invited to a group session run by the project's coordinators and befrienders.

The service was launched in 2012 initially as a pilot scheme but now has funding secured until 2017. It is run by local charity Autism West Midlands, who train the befrienders.

Ian Staples, Walsall's Lead Commissioner for Disabilities, says: "The myth is that people with autism do not want social interaction, do not want to engage. But that is just wrong.

"The service is a little bit different from a befriending scheme for older people. It has to be. Each of our volunteers under goes training to learn about the condition and how to handle and communicate with clients. The relationship can take months to build up."

Feedback from the scheme has been incredibly positive. So far 26 people have benefited and there are 22 active befrienders.

Referrals come from a variety of sources, including social care, the voluntary sector and via self-referral.

"We tailor our approach to the individual and are quite flexible, but there is a structure to it," says Mr Staples. "We aim to provide the support for 12 to 24 months. The idea is that the befrienders are able to help build up confidence and help them make links with their local community.

"For example, they may start doing some sporting activities and then get them involved with a sporting club. The volunteer helps ease that transition and then can gradually reduce contact. It is very important to get that right and do it in a structured and clear way."

John, 22, is typical of the people who have been helped. Before getting involved in the scheme, he was anxious and struggled to communicate and engage people in conversation. He would not even answer the door.

But after he took part, his life completely changed. He now travels on public transport alone and is able to hold conversations on a broad range of topics.

His mum says: "Every time they come, he is much more cheerful and smiley. He comes down to answer the door and to see them off and is always in a good mood afterwards".

The benefits are not just felt by the individuals with ASC. Feedback from parents and carers shows the service has acted as an informal form of respite care for them as well.

Contact:
staplesi@walsall.gov.uk

Liverpool: helping with employment

Research suggests people with autism are often unfavourably treated by employers. But the Liverpool Asperger Team has been doing its bit to help people with autism find jobs by running employment workshops.

Those looking for a job are invited for one-on-one sessions with an adviser who helps them with everything from CVs to help taking part in volunteer schemes to gain experience.

Clinical Psychologist Dr Frank Chapman, who is the clinical lead for the team, which is part of the Mersey Care NHS Trust, says: “We have always helped people with employment whether that is representing them at employment tribunals or just giving them general advice and support. We have also referred them on to dedicated employment agencies”.

“But I guess we wanted to see what else we could do. People with Asperger syndrome and autism have a lot to offer in the workplace.”

“We want to do proactive things like this with employers,” says Dr Chapman. “It is important to provide support to people with the condition, but you also need to engage with employers to make this work.”

The support on employment is just one element of the help that the team provides. It was originally commissioned in 2003 to respond to the needs of adults with Asperger’s Syndrome who were perceived as “falling between mainstream and learning disability services”.

It can provide input from a number of different professionals including nursing, clinical psychology, social work, clinical specialist in Asperger syndrome and assistant practitioners.

The service has assessed over 1,500 people since its inception and currently provides services for 247 people.

This includes everything from assessments and diagnosis through to advocacy, crisis intervention and access to specialist services and support groups.

Help is also offered to people wanting to go to college and higher education and in finding and identifying appropriate housing.

Support and guidance is also available to carers including regular awareness training, information and advice, contact with other carers, specialist support in caring for their relative and support with accessing assessments and benefits.

The team also organise two social inclusion hubs, which offer group-based clinical and social interventions to help service users meet others with similar difficulties to them, to develop their skills and social networks and to reintegrate into their local communities.

This has led on to services users creating their own social groups which have gone on to become self-running – some of which have been going for 10 years.

Contact:

frank.chapman@merseycare.nhs.uk



Local Government Association

Local Government House
Smith Square
London SW1P 3HZ

Telephone 020 7664 3000

Fax 020 7664 3030

Email info@local.gov.uk

www.local.gov.uk

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