

Supporting
people with

autism

Many people we support are on the autistic spectrum - some are able to live independent lives with limited support while others require on-going, specialist full-time support.

This leaflet describes just some of the ways we can support you – or someone close to you – to live the life you choose.

We offer a wide range of options for your support. This can be for just a few hours a week – perhaps to help you to pay your bills, manage your budget, do your shopping, to access the community, go to college or to get a job – or up to 24 hours a day.

We can support you to live independently in your own house or flat or to share with others. We can also support you in your family home.

Whatever support we provide, we will work in partnership with you, your family and other key people in your life. We use Person centred

Active Support, which means giving you enough help so that you can get involved in activities and meaningful relationships - whatever your abilities - so that you can gain more confidence and self-esteem.

We use recognised techniques such as SPELL* and PECS* - so that we can support you the way you want and need – and to help you to feel both safe and secure and to live a fulfilled life. We employ local support staff but also provide national and regional back-up from senior managers and staff with a range of specialist skills.

*see back page for definitions

United Response is an award winning, national charity, working throughout England and Wales. For 40 years we have been supporting people with life changing conditions to be more independent and take control of their lives.

How we will work with you

Everybody has different likes and dislikes, needs and wishes. So, we put you at the centre of your support and build our support around you – not the other way round.

■ We will work closely with you, and those important to you, to find out what is important to you and for you so that we can support you in the way that you want.

■ If you have routines which are important to you, we will work around you and the things that matter to you.

■ When things change, we will put structures in place so that you know what to expect and we will work with you at your pace, giving you the time you need to respond.

■ We will get to know you to understand how you experience the world and create an environment that you feel safe and secure in.

■ We will find out what makes you anxious - for some people this could be being touched, flashing lights, getting too hot, smells, colour schemes, sudden noises, too many people around or other things - and we will adapt your environment to reduce any anxiety you may be experiencing.

■ We will also provide opportunities for you to experience new things in a way that you are comfortable with.

■ If you want to learn new skills we will support you to do this - whether this is at home or going to college.

■ If you want to find a job we will support you to do this. We will help you with job applications, interviews and travel. We will work with your employer to help them understand you and how you communicate.

■ We will work with you so that you are actively engaged with your life; we will support you to do as much as you can, so that you are part of what is going on around you.

■ We will involve you in every aspect of your support to make sure you know and are comfortable with what is happening.

■ We will help you to pursue your interests and find new ones.

“ We acknowledge people with autism can experience high levels of stress and distress, particularly when they are in highly stimulating and demanding environments. ”

The Autism Act 2009



Communication

We will get to know you and how you communicate so that we can learn to interact with you in the way that you like.

If you do not use words to communicate, we will find a way for you to be able to tell us what you want to say - this could be through using pictures, prompts, objects or colour coding.

We are experienced in providing social and communications support. So, if you find it difficult to understand what people mean or find it difficult to talk to people, we will support you to make the situation easier.

We know that you might feel socially isolated so we will create opportunities, and support you to feel more comfortable to meet new people and make friends.

Communicating with people on the high end of the autistic spectrum isn't always easy. However, by finding the right technique, United Response staff were able to make a huge impact on John's life.

When we started to support John* in 2006 he liked his own company and preferred objects to people. When meals were served he didn't get involved, and only approached staff for few basic requests: for a biscuit, for some yoghurt, to use the computer or to ask people to leave him alone.

Over time, John's love of objects became obsessive. Staff would respond to his requests because they thought this would make him happy, but it didn't. He would receive the object he wanted, become bored and throw it on the floor.

John's insular nature and unsocial behaviour also proved difficult for his housemate. It was time to take a different approach.

Recognising that John didn't respond when they talked to him in long sentences,



“ All adults with autism are able to live fulfilling and rewarding lives within society that accepts and understands them. ”

The Autism Act 2009

John*

support staff tried objects of reference and fewer words to guide him through different parts of the day. When preparing for a day out, they turned off his music, so there were no distractions, showed him the keys to indicate leaving the house and waited by the front door. They waited patiently for up to 15 minutes, so he could process what they were suggesting – and then watched as he voluntarily walked towards the door.

“ Recognising that John didn't respond when they talked to him in long sentences, support staff tried objects of reference and fewer words to guide him through different parts of the day. ”

The same simplified approach encouraged John to engage with everyday household tasks. Whereas before he would guide staff to the fridge if he

wanted a yoghurt, waiting at the table for them to bring it to him, now with prompts and coaxing, he voluntarily takes the spoon out of the drawer and takes the yoghurt to the table himself. He had never done this before – engaged with a task and with the people supporting him.

By using intensive interaction techniques, such as copying his sounds and moves when he danced to his favourite music, communicating with him became easier. He responded by pulling staff to dance with him and looking them in the eyes, something he started doing more than usual. Soon, they began to hear him giggle and laugh more often too. He now helps to make tea, plays ball in the garden with his housemate and spends less time on his own.

His parents are thrilled with the change in their son. He stays with them regularly and they have told his social worker and the council how much his life has improved.

Emma, United Response Service Manager

*Name has been changed

“ We will help you to pursue your interests and find new ones. If you want to learn new skills we will support you to do this. ”



Case study - Michael*

We started supporting a young man of 18 last year who had been diagnosed with Autism when he was three. Michael* had been living at home with his parents and attended a school for people with special needs. Michael does not communicate verbally and experiences sensory overload in certain situations.

This meant that his parents had not been able to take him out for some time as he would get overheated in the car and become very anxious - this would cause him to flap his arms very fast and scream at the top of his voice. Also, they had never been able to re-decorate the house or move anything, as when Michael came home from school he would scan everywhere to check that everything was in the same place it had been when he had left that morning.

His care plan from social services stated that he had severe challenging behaviours which included grabbing staff, banging his teeth with pliers, and eating and drinking everything around.

We started with small steps, getting to know him and observing his routines and very soon we began to see a wonderful, tactile person who would come over and stroke your arm, lay his head on you, look into your eyes and smile.

Since then Michael has gone from strength to strength and has built up a great rapport with all the staff. He can now do things like help to prepare food and Hoover his room with hand on hand support. He also takes his washing and puts it in the machine and has learned how to dress and undress himself.

So that Michael can make choices and take control of his life - what he wants to eat, wear or do - we communicate with him using PECS, Makaton and gestures. He also takes us to, or points at, something he wants.

We have tried lots of different things with Michael and although he may still get anxious from time to time, it only lasts for seconds. We have got to know him well enough to be able to calm and reassure him, and he trusts us enough to know it will be ok.

Michael needs 2-1 support to go out as he can become very anxious. When this happens he stops in his tracks and it is hard to get him to move forward. He can have sensory meltdown as well which can cause him to flap his arms rapidly and jump up and down, or run off at great speed.

His social services support plan said that he wasn't allowed anywhere near water as he would run into it. Concerned that he was not experiencing the outside world, we carried out a risk assessment of a nearby park which had a fenced off lake. On his first trip there when he saw

the lake he set off running with me, and the other staff member close behind. He stopped by the fence and began flapping and screaming - he was very red and we stood making reassuring gestures and using softly spoken words to try to calm him down. Just then it began to rain very heavily. Michael stood there with rain pouring down on him and he began to laugh. He looked at us getting wetter and wetter and he laughed even more. He took my hand and we walked around the park. It was wonderful to see him so relaxed, smiling and happy.

When Michael's parents came for a visit recently they could not believe it when he laughed as it was something they had not heard him do in a long time. He is continually developing new skills and we are learning more things about him all the time. He has a wonderful character and his staff really enjoy supporting him.

Oh, and we do not have to have everything in the same place! We arranged his room as it was at home, so that he has a place he can go that is a familiar environment for him, but he is very adaptable to things being moved around in the rest of the house and it does not faze him.

We are very excited to see how he continues to gain more control of his life and become more independent!

Liz, United Response Service Manager

*Name has been changed

About us

United Response is a values-led charity and we believe that everyone – including those with profound disabilities - has a great deal to offer the world. We work with every individual so that they can fulfil their potential.

We constantly seek to learn from the people we support, their families, our staff and the outside world on how we can develop what we do and improve our person centred approach to support.

Although we are a large organisation, our support is devolved down to local managers and support workers who are part of the community where you live.

Our local staff are supported by specialist national teams such as our Practice Development team, which works with the foremost thinkers and practitioners in social care (examples include Michael Smull and the Tizard Centre) to ensure we are at the forefront of service delivery and quality.

Our Health and Safety team ensures that we are experts in safeguarding and well-being, while our innovative Quality Checkers make sure that our services are judged by the people who matter most: those who use them.

To watch videos, read case studies and much more, about the way we work visit our website

 www.unitedresponse.org.uk

or if you would like more information on specific areas of support please contact us:

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* Definitions from front page

PECS - The Picture Exchange Communication System (PECS) helps people with a variety of communication challenges, to learn how to communicate their wants and needs by using pictures whether they are at home, at work, in school or out in the community.

PECS begins by an individual asking for what they want by selecting a picture of it, eg a cup of tea, and then progresses by learning to use pictures to make sentences or to express preferences. In the more advanced phases, individuals learn to answer questions and to comment.

SPELL - SPELL, which was developed by the National Autistic Society, is a framework for supporting people on the autistic spectrum. It uses person centred, socially valid approaches to reduce the more disabling effects of autism, encourage and promote the strengths of autism and overall improve the quality of people's lives.

The five key elements of good practice within the SPELL framework are structure, positive approaches and expectations, empathy, low arousal environments and links to form an holistic support approach.