Transforming Care:

Supporting people with learning disabilities, autism and challenging behaviour to live happily in their local community

Supporting people to move back from out of area

United Response is an award winning charity that supports disabled people to live the life they choose. We have a wealth of experience in supporting people with complex disabilities – many of whom display behaviour which challenges – to live successfully and happily in their local community.

This experience includes supporting people to move out of long stay institutions, including assessment and treatment units and back from "out of area", working with young people in transition and providing bespoke housing management and support solutions.

It also includes pioneering Active Support as a way of enabling people with even the most complex needs to be involved in all aspects of their lives.

This leaflet sets out our approach to supporting people with complex needs and who may display behaviour which challenges; shows how Active Support is essential in underpinning Positive Behaviour Support, and details how we go about supporting someone to move from a long stay institution or Assessment & Treatment Unit to live happily in their local community.

United Response

support that changes with you

What is Positive Behaviour Support?

Challenging behaviour occurs as a result of a complex interaction between the individual and their environment and has been defined as *"behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion".*

Positive Behaviour Support is *"characterised by educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments".*

At the core of Positive Behaviour Support is a recognition that reacting only to the occurrence of challenging behaviour, the use of 'off the peg' responses and of punishment, are limiting and counterproductive strategies. Good Positive Behaviour Support must cover both how to respond to a person's challenging behaviour when it occurs (**reactive** strategy) and what actions should be taken to reduce, over time, the need for the person to behave in ways which are challenging (**proactive** strategies).

These **proactive strategies** focus on:

- The quality and range of relationships and activities the person participates in
- The physical surroundings of the person and who he/she interacts with
- How predictable these factors are
- How staff and others communicate with the person
- How those who support the person manage occasions where there might be a risk of challenging behaviour occurring
- How other people might improve their understanding of the person and his/her behaviour.

However, successful Positive Behaviour Support relies on other person-centred approaches being in place, including:

- Person Centred Thinking and Planning
- Effective Communication
- The National Autistic Society's SPELL framework for supporting people on the autistic spectrum
- Active Support.

What is Active Support?

Active Support encompasses a range of approaches which aim to provide **enough** help to enable people to participate successfully in meaningful activities and relationships so that they:

- Gain more control over their lives
- Develop more independence
- Become more included as a valued member of their community irrespective of degree of intellectual disability or presence of challenging behaviour.

Active Support focuses on both:

- The skills of staff in enabling engagement and
- The capacity of the service to provide accessible opportunities in a structured and predictable fashion.

Active Support has been shown to be important in determining the quality of life of people with learning disabilities and in particular in increasing people's participation in daily life, social and community activities as well as increasing people's skills, adaptive behaviour and choice.

The primary outcome of Active Support is engagement in meaningful activities and relationships but the way it looks in practice will vary depending on the individual requirements of the person being supported and the nature of the activity or interaction being supported.

There are **4 essential components** to Active Support which promote engagement in activities and relationships:

1. Every moment has potential
2. Little and often
3. Graded assistance
4. Maximising choice and control.

92%

of people we support have regular contact with family

Moving on from an Assessment and Treatment Unit – Trudy's story

Trudy grew up living with different family members until she was 19, then was placed in various care homes. Each placement broke down due to the levels of challenging behaviours she presented. She was also subject to abusive work practices which led to safeguarding and Trudy was then placed in an Assessment and Treatment Unit, where she stayed for 18 months.

Trudy is now 31 years old and has a mild learning disability, hydrocephalus, spina bifida and support needs with her mental health, requiring 1:1 support 24 hours a day. When we first met Trudy, she was extremely anxious, lacking in confidence and had low self-esteem. She was always feeling that she was going to be in trouble and so was constantly seeking reassurance. Trudy was on regular PRN medication to help calm her down when her anxieties and behaviours escalated.

When we were asked to meet up with Trudy's care managers at the unit early on in the process, they initially thought that Trudy would need 2:1 support. The authorities had prepared costs for this but we didn't think that was in Trudy's best interests; we wanted to engage with her and learn about her first before making the decision. After undertaking the proper assessments, it turned out that Trudy didn't need such intensive support, which saved the authorities a lot of money and got the best outcome for her.

Prior to moving from the Assessment and Treatment Unit, we spent 6-8 weeks visiting Trudy most days; building a relationship with her that enabled her to feel confident with us and allowed her to learn that she could trust us. We took activities to the unit to maximise the opportunity for engagement and interaction. We also used to take a laptop and together completed person centred contract documents that identified and told people how Trudy wanted and liked her support, how she communicated and how she wanted her life to be.

During this period, we started to take a lead in providing Trudy's support and the unit staff took a step back. This enabled us to increase her opportunities to access the community. Trudy started to put a lot of trust in us and wanted us to be around; she would always ask when we would next be visiting and, on days that we weren't visiting, she would ask if we could phone her, which we always did.

Trudy felt that days at the unit lacked the opportunity to be independent; meals were prepared for her and she had to wait for authorisation for most things. Trudy did go out occasionally subject to staff availability, though she would get upset when she knew and saw that others were leaving the unit to live in the community.

At that time, family contact was inconsistent due to her family's concerns about taking the children into the environment of the unit. One Christmas, Trudy was the only "patient" left on the unit as others had gone home or were spending Christmas with their families – this was a terrible time for her. She often felt she was not allowed to go out because she couldn't be trusted.

Trudy now lives on her own and prefers this; she would find it difficult to share a house and support with others. Once we had started supporting Trudy and found a bungalow that we and other professionals thought was suitable for her, we involved Trudy in the process and invited her to visit. She made the decision that she wanted to live there. We then supported Trudy to think about décor, colour schemes and things she wanted and needed to buy. This was an exciting and motivating time for Trudy as she was really looking forward to her new life in her home.

> Family feedback has noted how well Trudy is doing since leaving the unit.

We have been supporting Trudy for 13 months now, and in that time she has interviewed and selected her own staff with support. Trudy has challenged boundaries with staff and will test us out but she has a strong support team in place whom she trusts and feels confident with. A support plan and risk assessment devised by Trudy with support is in place for staff to follow consistently, in line with the way Trudy wants and likes her support.

Since we have supported Trudy, she has become a lot more confident. She is a lot more independent now that she has choice and control over her life. She now goes to college and is studying drama, art and cookery which she enjoys. She likes the social side, going to discos, pubs, hairdressers, gyms and coffee shops. She enjoyed holidays in Skegness and in Spain and went on both with just one member of staff.

She has not had to use PRN since we have supported her and rarely feels the need to seek reassurance. She has a great personality and a great sense of humour!

Trudy's relationship with her sister and family has improved, they speak each week on the phone and she has had sleepovers at her sister's house. In their feedback her family has noted how well Trudy is doing since leaving the unit.

Active Support and Positive Behaviour Support – how they fit together

Active Support underpins Positive Behaviour Support because of its emphasis on systematic changes to the whole environment AND in the way services focus on promoting the quality of life of the people they support, a critical element of reducing challenging behaviour:

> Challenging behaviour is generally a rational, normal response to adverse circumstances. Active Support recognises the common need for predictability, for sensitive and flexible help to engage successfully in everyday activity, to make choices and to exert control over how we lead our lives day to day. Consequently, Active Support provides conditions in which challenging behaviour generally decreases, particularly by improving people's quality of life: helping people to develop new skills, gain self-confidence and experience choice and control. For many individuals, Active Support delivers enough of what they need to render challenging behaviour unnecessary. And, whilst a number of individuals will require the intensity and precision of Positive Behaviour Support, the majority would benefit significantly (and sufficiently to minimise challenging behaviour) from the implementation of Active Support.
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> Where Positive Behaviour Support is needed, its effective implementation is dependent on a number of service characteristics that are inherent to Active Support, including objective assessment, analysis, monitoring and evaluation, coherent and realistic planning, flexible and sensitive implementation and a structure that facilitates rational and proactive support.

Over

68%

of people we support are engaged more than 50% of the time

Active Support at United Response

United Response has long pioneered active support as a way of engaging people with even the most complex needs in all areas of their lives. Beginning in 2000, working in partnership with the late Professor Jim Mansell CBE and the Tizard Centre, we have put a comprehensive programme of training and practice leadership in place. And we have tracked our progress with an annual evaluation which sees 20% of our services selected to be involved each year.

In 2012, 46 Services, supporting 162 people, were evaluated by members of the Practice Development Team. Services were selected by the Tizard Centre to provide a representative sample of service type and individual needs. Evaluations consisted of:

- A service visit and observation
- Questionnaires about the people we support (providing information on the needs, skills and characteristics of the people we support)
- Staff questionnaires (providing information on practice leadership, knowledge, person centred thinking tools and training information).

The Tizard Centre analysed the information to provide quantitative data and the results show that:

- 92% of people we support have regular contact with family and an additional 59% have regular contact with friends (not people who are paid to support them)
- On average, people were engaged 61% of the time
- Over 68% were engaged more than 50% of the time
- 73% had Active Support Measure scores in the top band.

A comparison of data from Measuring the outcomes of care homes: Final Report (Netten et.al. 2010), The Skilled Support Survey (Beadle-Brown et.al. 2012) and studies into the implementation of active support in Australia (Mansell et.al in press) found that United Response's Active Support Scores were higher – in many cases significantly - than other organisations.

On average, people we support are engaged

61%

of the time

The impact of Active Support - Geraldine's story

Geraldine is a middle-aged lady who lives with three other people in a suburb of a city in the south of England, supported by United Response. She has a moderate learning disability and a visual impairment, and lived for some years in a number of small institutions before moving to her current home. Geraldine is often charming, considerate and affectionate. She has a number of skills and enjoys interacting with others. However she frequently experiences episodes of acute distress, shouting and swearing, jumping up and down, banging her feet and hands hard on the floor, and scratching her face so repetitively that it bleeds. Staff struggle to support Geraldine when she behaves in this way and find that their reactive strategies have little effect beyond supporting her to calm down a little, before the next episode.

It had been suggested that Geraldine was the victim of abuse in one of her previous placements, so attempts were made to establish an intervention that would help her recover from the psychological damage involved. Sadly, despite a number of attempts involving members of the local learning disability team, no-one was able to make any progress in this area because of Geraldine's cognitive impairments. Other proactive strategies included teaching her coping skills (so she can better deal with conflict with her co-tenants) and improving lighting and the use of visual contrast in the décor and fabric of her home so that she can find her way around better. None of these developments had an impact on the frequency, duration or intensity of Geraldine's challenging behaviour.

However, a new United Response manager with expertise in Active Support was appointed to lead practice in Geraldine's service. One of his first acts was to change the way that staff support, and the events of the day, were planned and organised. In particular he focused on increasing the predictability of what happened when, and with whom. Some of this involved scheduling existing activity in a more structured way, but even more predictability was enabled by increasing the amount that Geraldine and her co-tenants were involved in everyday activities around their home – things that staff might have done by themselves in order to be "kind" to the people they supported. Rapidly, Geraldine's challenging behaviour diminished to a very low level (and when it happened it was usually because staff had forgotten to maintain the agreed structure).

Furthermore, many of the old strategies the service had tried now proved effective – they weren't wrong, they just weren't part of something that enabled Geraldine to make sense of her world. Active Support brought the structure and coherence that she required.

Setting up a new service for people with substantial levels of challenging behaviour

We have extensive experience of supporting people to move out of long stay institutions and assessment and treatment units across the country. To capture this learning, we have developed a "New Referral Checklist" to help staff in setting up services for people with substantial levels of challenging behaviour.

Our approach includes:

Developing partnership agreements between stakeholders:

- ☐ Developing a formal agreement for roles and responsibilities before, during and after the move
- ☐ Ensuring contracts are agreed with organisations or companies that will be providing services (e.g. housing, training etc) after the move
- ☐ Reviewing any service specification
- ☐ Ensuring funding arrangements are agreed for all elements including overlap
- ☐ Developing clear role descriptions (over and above the standard job descriptions) for the Service Manager and Team Leader in the new service
- ☐ Ensuring agreement is in place to recruit and appoint the Service Manager early in the process.

Gathering information about the person to inform service design

Being clear about the requirements for Service Manager's Skills and Knowledge, which must include competent Practice Leadership, particularly in demonstrating good practice in supporting people with challenging behaviour

Planning staff recruitment and the development of staff skills and knowledge

Determining an Appropriate Living Environment that is:

- ☐ Physically suited to the person
- ☐ Large enough to accommodate the person, and the number of staff who will be on duty
- ☐ A suitable location (e.g. proximity to family and friends).

Clarifying and agreeing any necessary legal considerations.

Our "bottom line" requirement list of components that must be in place before a person with significant levels of challenging behaviour moves in to a new service is:

Practice Leader and an agreed percentage of staff in place for 3 months

Staff Rota and staff to deliver it

Shift Plan

Emergency Plan and contingency protocols On-call and/or standby arrangements

Positive Behaviour Support Intervention Plan

Clear record of the person's routines

Provision for debriefing staff, more frequent supervisions and shift handovers

Provision for frequent team meetings

Daily time to review service

Support from external professionals

Mental capacity assessments re physical interventions, Deprivation of Liberty Standards, etc, agreed by the Multi-Disciplinary Team.

This checklist (abridged here) is also supported in every case by a thorough and comprehensive project management plan relevant to the circumstances.

> "The average cost per person at Winterbourne View was £3500 per week."

Putting the theory into practice - Adam's story

Adam is a determined individual who knows what he wants from life. He is friendly and welcoming and enjoys domestic endeavours – such as housework and cooking – as well as visiting the cinema and shops. He leads an active lifestyle and frequently goes bike riding, walking and dancing and values his family time with whom he recently celebrated his 40th birthday at a local pub. United Response became involved in supporting him in 2005 whilst he was still at a long stay hospital.

Adam moved to a unit of a long stay learning disability hospital in the North East of England in 1984. As a strong-willed person, he often became frustrated by being denied the choices he wanted in life and he often exhibited challenging behaviour which ranged from self-harm to threatening actions against other people. This often led to him being physically restrained and staying on the ward for most of the day.

United Response began our involvement with Adam when he was 35 years old. We looked to overcome the issue of a lack of intensive support by planning a supported living scheme for him around his local area but this was soon abandoned due to health and safety concerns.

We then developed a United Response staff team in the hospital and staff members worked alongside the hospital staff. The number of United Response staff was increased over time and, over the period of a few months, the original complement of two staff members was increased to four and continued until full capacity was reached and Adam had 12 people who worked full shifts around him.

> The result was dramatic. Gradually, as we got more involved every day, Adam's challenging behaviour ebbed away.

Over the course of this transition of support staff, Adam was also moved to an upstairs ward where he had his own bathroom, sitting room, office and a shared bathroom. When United Response eventually got the go-ahead to provide full support to Adam in the hospital, the staff then found themselves in a position to seek to help Adam with his challenging behaviour.

The result was dramatic. Gradually, as we got more involved every day, Adam's challenging behaviour ebbed away. He didn't receive a full restraint during the last four months and his behaviour improved so much we only used body restraint to calm him down.

But how was this improvement achieved?

Steve, the United Response service manager who managed the process, says:

"You have to be around Adam. You have to know the way he looks, his behaviour, what it tells you. It has to be an approach centred entirely on him. Only then can you help him overcome the difficulties he has.

> When he moved in, Adam was given 2:1 residential support and 3:1 support in the community due to his history of challenging behaviour but, such is the progress he made, this level is gradually being reduced.

"We noticed that Adam had trouble expressing himself and would often say the wrong thing which made him agitated. For instance, when we asked Adam if he wanted a cup of coffee and he said no when he meant yes, we would give him the chance to change his mind. This would avoid any distress and thus any challenging behaviour which might otherwise have arisen. Adam's physical restraints decreased because he had more input into his own life and more freedom to choose what he wanted - even simple things like choosing when to have a cup of coffee.

"He does have off-days, but it is usually a case of looking into it and finding out the cause. More often than not, we find out that he is just unwell."

After five months, we asked the local authority if Adam could have a vehicle solely for him whilst he was in hospital so that he could go out every day. Then, seeing that Adam responded well to being given his own choices, we asked him what he wanted from his life. He expressed a desire to move to new accommodation on his own and plans were put in place to relocate Adam to a single-person

supported living service. Adam told us that he wanted to live on his own in a rural setting. He also wanted more specific facets such as having what he called 'a bubble bath' and to be near to a chip shop. We enlisted the help of a local housing association who helped us find his ideal house. In the end, we managed everything but the chip shop!

Adam was able to move into a large, rural house which he had chosen for himself. He now has a vastly improved level of personal choice and has been involved in deciding everything from the location of his new house to the colour of the walls.

And as Steve says, "He is a million times better for it."

When he moved in, Adam was given 2:1 residential support and 3:1 support in the community due to his history of challenging behaviour but, such is the progress he made, this level is gradually being reduced.

Successful support centres on knowing the person and responding to their needs and so working closely with families is vital. Families have a wealth of information and can provide an immediate insight into an individual and why they might be behaving in a certain way. So, it was very important that we worked alongside Adam's family to show them that his new living arrangements would not leave him in a vulnerable situation.

Steve adds: "Initially, I don't think Adam's family were fully confident that we could provide the right level of support for him. But we have proved that we can as Adam is not as challenging as before and his family can see this. As a result, we have been able to win their trust and they are comfortable with the progress that he has made."

Cost savings

Staying in an assessment and treatment unit isn't just restrictive, it's also very expensive. The average cost of a placement at Winterbourne View was £3500 per person per week and yet supporting people in their local community is not only much more effective in supporting independence and choice, it's also cheaper.

We look very carefully at where efficiencies could be made, reviewing services with people we support and others including care managers, using our outcomes focused person centred support plans, and performance indicators to ensure that the intended outcomes are being achieved and the person's needs are being met in a way that represents value for money. Any proposals to make efficiencies involve the views of people we support, carers, family members and others, including independent advocacy which we encourage all people we support to access and must be accepted by the person and the local authority before they are implemented.

We complete equality impact assessments when changes are made to a service and our robust risk management process and prevention of harm and safeguarding policies will ensure people's needs will continue to be met in a safe and a managed way.

We increasingly use Assistive Technology, where appropriate, to identify and implement cost effective and often cost saving technology to enhance people's independence, and give greater flexibility to how they are supported. Examples include replacing sleep-in staff, using technologies to detect seizures, nocturnal activity and general monitoring of any health conditions people might have.

We also work with people to increase their community connections and develop circles of support. This allows people to make choices about who support them and develops "none paid" relationships within their communities and with other agencies.

Case studies

In one service, we reduced waking night staff from two per night to one with a sleep-in. Efficiencies at this service made in partnership with the local authority saved approximately £32k.

> "Efficiencies saved approximately £40K"

In another, we worked with people we support to reduce some of the 3:1 support down to 2:1. This was achieved through our methods of Positive Behavioural Support and Active Support. Efficiencies at this service made in partnership with the local authority saved approximately £40k.

Overcoming challenges – John's story

John is in his 40s and began being supported by United Response in 2008, after spending most of his life in a long stay hospital. He is on the autistic spectrum, has learning disabilities, is deaf and has other sensory impairments. John's pen profile was very negative – stating that he caused damage to himself, other people and property. It referred to instances where he had bitten off someone's toe, attacked people and smashed through a window. He was subjected to PRN on a regular basis throughout his years there and had clearly been labelled as a violent and difficult individual – essentially, a lost cause.

His previous care workers, who were transferred with John to our team, described him as "poisonous". To add to this reputation, John had been described as "the most dangerous man in the area".

Our service manager worked closely with our practice development team to put in place Positive Behaviour Support and good Active Support plans and approaches in order for his support team to work with John properly. These included looking for and changing environmental and communication triggers and also engaging John in meaningful activities and relationships.

"His previous care workers, who were transferred with John to our team, described him as "poisonous". To add to this reputation John had been described as "the most dangerous man in the area"."

The approaches put in place ensure that John has consistent support which provides a structure to his life so that he is engaged and knows when and what will happen throughout his day. They also include spotting risky situations which might trigger John's anxieties with proactive approaches to minimise these but also reactive ones for when something happens. One example is when John is out walking, he is inclined to pick up and eat cigarette ends he sees on the ground. Over time, we have supported John with strongly flavoured snacks (chocolate covered coffee beans, liquorice sticks and extra strong mints). By offering him one in these situations, he is less interested in picking up the used cigarettes. These distraction techniques are all part of a range of Positive Behaviour Support approaches.

"John is now fully engaged with his life which includes taking part in arts and crafts, pottery, gardening, swimming, bowling, cookery and visits to a sensory room."

John is now fully engaged with his life, which includes taking part in arts and crafts, pottery, gardening, swimming, bowling, cookery and visits to a sensory room and the only incident of "aggression" in recent years was when he once moved someone out of his way. And his support team now are affectionate, understanding and empathetic whenever they talk about John.

73%

of people we support have Active Support Measure scores in the top band

Housing

Having the right place to live is something everyone needs and we know that getting the right housing for people with complex needs can have a significant positive impact on people's wellbeing, support needs and behaviours. Securing the right, community based housing and support solution can also provide really good value for money for all concerned.

People with disabilities often find it hard to secure the right accommodation and people with complex needs often find it even harder still. Not having access to the right housing is a major barrier to people moving back from out of area and out of Assessment and Treatment Units – and that's why supporting people to find the right housing in the right location is such an important part of what we offer.

We work with a wide range of housing partners including private landlords, housing associations and charities, to provide the people we support with access to the widest range of housing options possible. Our housing brokerage service helps people and their families understand their specific housing needs and secure the right housing solution. We also own and lease our own housing and our dedicated housing department manages all of our housing activities and provides housing management and landlord services to a significant number of people with disabilities, including shared owners.

Working with you

We would be very happy to discuss with you how we might be able to support you to move people back to your local community. To find out more, please contact us:

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NB: Names have been changed throughout to preserve the anonymity of the people we support.

United Response
support that changes with you

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