A Valued Life

Developing person-centred approaches so people can be more included

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Thank you to everyone who has taken part in the evaluation and this report, *A Valued Life, Developing person-centred approaches so people can be more included*. Particular thanks go to John Ockenden, Rebecca Whelton, Professor Jim Mansell, Bob Tindall and the people we support and staff who have contributed case studies.

Academic journal papers containing further analyses of the data are currently in preparation.
Introduction

United Response (UR) is a national charity with over 30 years experience of providing services for people with learning disabilities or mental health needs. Built around the changing needs of the people it supports, UR operates over 200 services across England and Wales and supports around 1,500 people. UR offers a range of person-centred support from supported living to 24-hour residential care, and support for people who want to work to find meaningful employment.

Many of the people we support have complex needs, including physical disabilities, hearing and/or visual impairments, and behaviour which challenges. Through our work we aim to provide high quality services to support people to become more engaged in day-to-day activities and, where possible, to live more independent lives. In order to ensure we continue to do this, we believe that it is important to evaluate the effectiveness of our work.

This report outlines a ground-breaking project carried out by United Response and the Tizard Centre to evaluate the impact person-centred approaches are having on the lives of people with learning disabilities.

This report has been written by Bev Ashman from United Response and Dr Julie Beadle-Brown from the Tizard Centre. The evaluation complements our ongoing quality assurance and auditing processes and makes a considerable contribution to disability research in the UK. The study is the largest study in the world focusing on the impact of person-centred approaches.
Glossary of terms

The following terms are used throughout this report:

**Meaningful activity** - Taking an active role in social, recreational, leisure or practical activities at home or in the community.

**Engagement** - When a person is actively participating in a meaningful activity or social interaction.

Mansell et al. [1] define engagement in the following three ways:

- doing something constructive with materials, such as vacuuming the floor, laying a table or loading a dishwasher.
- interacting with people e.g. talking or listening to them or paying attention to what they do – holding a conversation, watching someone demonstrate how to do something.
- Taking part in a group activity such as watching the ball and running after it in football.

**Active Support / Person-centred Active Support** - A way of helping people with learning disabilities to engage in meaningful activity and relationships as active participants. Instead of doing things for people or to people, it involves working with people to enable them to take part in all the activities of everyday life, no matter how disabled they are. Person-centred Active Support is a further development of Active Support, which has been refined to reflect the increasing emphasis on person-centred approaches.

**Active Support Measure** - An observation tool completed for each person giving a score of 0 (very poor performance) to 3 (good, consistent performance) on 15 different activity, communication and support elements in order to measure the implementation of Active Support.

**Practice Leadership** - Practice Leadership is when managers and senior support workers spend time teaching, guiding and demonstrating effective support and person-centred approaches to staff.

**Way We Work Framework** - A tool to enable staff to make the connection between the range of practice development methods being developed in all United Response services. These include person-centred planning, Active Support and communication strategies.
Summary of key findings

Through the project we were able to find out the following:

Increase in Person-centred Active Support

Over the last five years there has been a significant increase in the use of Person-centred Active Support – a way of using ordinary, everyday activities to encourage choice, engagement and to increase independence.

Increase in engagement

The engagement of people we support in meaningful activities has increased significantly. Overall, almost 50% of people showed increases in level of engagement.

The number of people largely disengaged decreased by 21%.

Increase in skills

75% of the people we support with severe learning disabilities have increased their skills and become more independent.

Person-centred Active Support and engagement

There is a direct link between the increased use of Person-centred Active Support within United Response and the increase in engagement.

Engagement of people with complex needs

UR supports many people with complex needs. Person-centred Active Support has made real difference to people’s lives across the board. But the most marked change has been amongst those with the lowest skills levels who have moved from being largely disengaged in 2000 to being engaged up to 50% of the time in 2005/2006.

The use of different forms of communication

The use of photos, pictures and other forms of alternative communication is a key part of Person-centred Active Support with 76% of staff reporting using them regularly with the people they support.

The importance of effective practice leadership

Person-centred Active Support is driven by example. Support staff are more likely to practice Person-centred Active Support when frontline managers show effective practice leadership.
The project

There is evidence that community-based services for people with learning disabilities provide richer physical environments. They also, through their higher ratio of staff, provide the opportunity for more intensive and rewarding relationships to be built [2].

While many organisations agree on the principles of community care and person-centred support, research tells us there is a wide variation in the quality of care and support provided.

A central concern is the extensive inactivity and isolation still seen in some community services [2,3].

Research shows that while non-disabled people are engaged, on average, for 90% of the time, people with learning disabilities living in community settings are engaged for an average of 11% of their waking day [3].

The extent to which people engage in activities going on around them has been used for many years to measure how well services for people with learning disabilities in the UK support people to achieve a better quality of life [3-7].

There are clear links between engagement, when a person is actively participating in meaningful activities and social interaction and quality of life [8].

Taking part in activities is often the basis for personal growth and development, for forming new relationships, increasing social inclusion and for choice and control over one’s life [1].

We would not necessarily expect to see the same level of engagement for people with severe disabilities as their non-disabled peers. This is largely due to the fact that many people with severe disabilities find it difficult to engage for long periods of time. However, studies have shown that people with severe and profound learning disabilities can significantly increase the extent to which they participate in meaningful activities.

Research into community services in the UK has identified two major factors which directly impact on the engagement of people with learning disabilities. These are firstly the abilities of the individual and secondly the amount of ‘assistance’ (instructions, guidance, prompting) provided by staff. The higher the level of assistance from staff, the higher the levels of engagement [9-16].
CASE STUDY

Andrea’s story

Andrea, aged 44, lives in York. She has a learning disability and does not communicate verbally. She has been supported by UR for the last 13 years.

Andrea used to live in an institutional setting, where most things were done for her. When she moved to a house in the community run by UR, staff found Andrea disengaged and her behaviour often challenged the service.

Staff worked with Andrea to find out the things she actually wanted to do. They came up with ways to support her to do those things. In each case it was a matter of adapting the activity to Andrea rather than the other way around.

An example of this was that to start with Andrea had no interest in preparing her own meals. Staff spent time with Andrea in the kitchen, so she could become familiar with its layout. They found that once she knew her way around the kitchen and felt in control of what was in the cupboard, she became a lot more confident about making herself a drink or snack.

Staff found out how Andrea preferred to communicate. They thought picture cards would work, but soon realised that using a form of signing called Makaton engaged Andrea a lot more.

Staff persistence paid off. Andrea’s skills increased and three years ago, Andrea and her support team decided she was ready to move on from the residential home, where she lived with five other people, to her own tenancy, sharing a house with just one other person.

Although Andrea had already developed many of the skills she needed to live in her own home, she was not used to living in such a busy area and was unsure of her surroundings.

Staff helped her to learn and memorise her route back to the house and went out every day with her so she knew that the road and area were safe. Andrea is comfortable in her surroundings now. In the last year she’s been using buses for the first time and with support she now travels to the supermarket, where she does her own shopping.
Person-centred Active Support

Active Support is a way of working designed to increase the effectiveness of staff support given to people with learning disabilities by tailoring support to the individual's needs. It is based on work originally carried out by Mansell and colleagues in Andover in the 1980s [17], and refined in subsequent years [1,18,19].

Person-centred Active Support is a way of helping people with learning disabilities to engage in meaningful activity and relationships as active participants. Instead of doing things for people or to people, it involves working with people to enable them to take part in all the activities of everyday life, no matter how disabled they are.

“Person-centred Active Support involves providing enough help to enable people to participate successfully in meaningful activities and relationships, so that people gain more control over their lives, gain more independence and become more included as a valued member of their community irrespective of the degree of intellectual disability or the presence of extra problems such as challenging behaviour.”

(Mansell et al. 2005)

Research on the implementation of Active Support, in pilot projects, provides clear evidence that people can significantly increase the extent to which they participate in meaningful activities if staff adopt this approach [11,13, 20].

CASE STUDY

Josie’s story

Josie has been living at a house run by UR in Suffolk for the last eight years. She has limited mobility and uses a walking frame. In recent months, walking has become more difficult for Josie. But staff at the house have come up with a new way of motivating her to stay mobile each day.

They have produced a words and pictures table to show all the day-to-day activities people at the service participate in. The table includes everything from preparing the tea to getting the post and newspaper and helping with maintenance checks around the house.

Each person living in the house has their own coloured stickers which they put on the chart once they have completed a task. Each month the information from the chart is transferred over to a monthly record, so staff can get an overview of who has done what. This helps staff to spot patterns and adjust their support accordingly. The staff also keep a photo record to help people living in the house remember all the things they have achieved.

Since introducing the activity chart and the photo record, staff have seen a real increase in people’s engagement in the house. Each person can now see exactly what they have achieved and staff believe this has acted as an incentive for people to get involved and try out new things. With support, each person in the house now prepares their own tea and cleans their own room; things they didn’t do before.
In order to fully implement Person-centred Active Support, especially for people with severe and complex needs, it is necessary to use a combination of approaches. These could be communication strategies and positive behaviour support. These combine with person-centred planning for a fully integrated person-centred approach.

In 1998, United Response introduced Active Support as an organisation-wide approach [21]. This was the first time the approach had been adopted by a national organisation across a wide range of geographically dispersed settings. As well as providing Active Support training, we identified the implementation of Active Support as a corporate objective. We developed organisational standards and carried out a review of organisational systems and structures.

David, aged 47, has been living at a house run by United Response in Middlesex for the last 10 years. He has a severe learning disability and presents behaviour which makes it difficult for him to engage in activities. David’s support workers have always found it difficult to get David interested and involved in things, but have used Person-centred Active Support to find ways of helping him to become more engaged. Working one-to-one with David, they have learnt that planning activities in advance, cutting out lots of verbal communication and using really clear gestures and objects of reference means that David can get more involved in small steps throughout activities.

Staff have seen a real increase in David’s skills and level of engagement over the last two to three years. David now participates in several household activities such as doing the laundry, putting rubbish bins out, buying groceries, laying the table, carrying plates and wiping the table. He has also become more confident.
To promote the implementation of Active Support and monitor progress on this corporate objective, UR carried out a study in 1999/2000 with the Tizard Centre at the University of Kent, in Canterbury. This was to look at the needs and characteristics of the people we support and the features of residential and supported living services within UR. This study would provide a baseline against which we could benchmark for the future.

343 people with learning disabilities living in 76 residential and supported living services in England took part in the study. We visited each of these services so we could observe levels of engagement and the way staff provided support. Observations were made over a two hour period and around a meal time, as this seemed likely to provide many opportunities to see staff providing support to people as they prepared, chose and ate their food.

The nature and quality of staff support was rated for the whole session using a 15 item rating scale called the Active Support Measure [22] for each of the people we support. At the same time as ratings of Active Support were made, the observer rated the level of engagement for each person being supported using a separate 4-point scale.

The baseline study provided evidence that a significant proportion of the people we support had substantial needs for practical help from staff. We found out the following:

- 80% of services included people with profound or severe social impairments.
- Three-quarters of services included people with very limited receptive and expressive communication.
- Almost all services included people with challenging behaviour.
- In half of the services, the management of people's challenging behaviour presented a severe problem at least daily.

At baseline, 35% of people were largely disengaged and only 13% of people spent more than 50% of their day engaged. The average score on the Active Support Measure was 52%. This indicated that most people were receiving mixed quality of support. Some people were receiving very good support while others were not receiving enough support to engage in meaningful activities and relationships.

For a small number of the services where Active Support had been introduced earlier, there was clear evidence that a person’s engagement in meaningful activity and their individual skills had increased.

Further statistical analysis showed that a person’s level of engagement was influenced by two factors: the skills of the person being supported and the type and level of support provided by the staff. This is consistent with other research.
Developing person-centred approaches

The baseline assessment confirmed that our decision to implement Active Support was well founded. The organisation invested in a number of key developments to ensure that the implementation of Active Support progressed.

Much of our work focused on developing the skills and knowledge of staff and their confidence in implementing Active Support.

This included developing information sharing, training, role definition and responsibilities for practice leadership. It also included building on existing supervision processes and staff development in services, to ensure a focus on Active Support. We made use of our internal expertise to provide direct assistance to front-line managers through bi-monthly practice development forums.

We recognised that effective communication is a gateway to providing the people we support with their desired and required support. We developed additional training and resources to help staff develop alternative forms of communication, utilising expertise from other areas within the organisation.

Following the publication of Valuing People: A New Strategy for Learning Disability for the 21st Century (Department of Health, 2001) we developed the Way We Work Framework to help staff see how Active Support, communication, person-centred planning, and other tools work together to develop integrated person-centred approaches for the people we support.
2005/06 evaluation

We carried out a reassessment of the implementation of Person-centred Active Support in 2005/2006. In addition to measuring progress against the baseline information, this study aimed to find out more about the values, skills and motivation of staff and the effect of practice leadership by managers.

People supported by UR were fully involved in the evaluation process. We made information about the evaluation available in an accessible format, using pictures and words. We also gave people the opportunity to feed back at different stages of the evaluation.

Evaluation procedures

Over a 14 month period, trained assessors visited 138 services, where they observed 469 people being supported in their own homes. 425 staff completed questionnaires about their experience and understanding of working with people with learning disabilities. Information was also collected about the skills and behaviours of the 649 people we support.

We sought consent from the people we support prior to the observation using an information sheet, which could be read out and/or supplemented with a range of alternative communication techniques. We made time for people we support to raise any questions they may have had about the evaluation, before and after the observation took place.

When an individual’s capacity to consent to the observation was uncertain, we used particular tools to help determine people’s preferences. If this was still too difficult, we weighed the risks against the benefits.

The final stage of the consent procedure was during the observation itself. For many of the people we support, it was only when they experienced having someone in their house to observe what was happening that they were able to make a real choice. We were therefore clear that consent was not static and could be withdrawn.

People were given the choice about whether or not they took part in the project on an ongoing basis and we were keen to ensure that those people should feel comfortable. If during the observation someone showed signs of being uncomfortable and/or upset by the observer’s presence, this was taken as evidence of withdrawal of consent/agreement and the observation stopped immediately.

CASE STUDY

Mary’s story

Before the visit to her home, Mary asked for more information about Bev, the person coming to do the observation. She also asked if she could make sure that person didn’t wear shoes which would make a noise on or mark the new wooden floors.

Bev sent Mary a letter telling her about her work and interests, along with a picture of herself, and wore trainers on the day she visited.

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Feedback and action planning

At service level this project aimed to provide an independent assessment of current support in services and give clear feedback to staff and the people we support. It also aimed to act as a tool for the continuing development of person-centred approaches and best practice within UR.

In order to achieve this we needed to ensure feedback was immediate and linked to ongoing support and action planning. We did this by combining verbal feedback and action planning with service and area managers within 1-4 weeks of the visit to the service. Written feedback, together with an accessible report, was also sent to managers, staff teams and the people we support for discussion at team and tenancy meetings.

As with the baseline assessment, this project was carried out in partnership with the Tizard Centre at the University of Kent. The Tizard Centre analysed the information to provide quantitative data to identify how particular factors impacted on the service provided. Feedback on this part of the evaluation was provided in Autumn 2006 in the form of presentations to Trustees, directors and area management teams, reports to services and accessible information for the people we support.
**What the evaluation tells us**

**Engagement**

The engagement of people we support in meaningful activities increased significantly. Overall, almost 50% of people showed increases in level of engagement.

In 2000, 35% of people were largely disengaged. This reduced to 14% in 2005/2006. The number of people engaged for more than 50% of the time increased from 13% to 31%.

In 2005/2006 people were engaged 43% of the time – 30% in practical or leisure (not just social) activities. This compares favourably to the findings of Emerson et al (1999) for example, who found levels of 11% non-social activity for a slightly more able group of people living in dispersed community settings.

The number of people in the most able group who were engaged over 75% of the time doubled (15% to 32%), while those spending most of their time disengaged dropped from 17% to 2% at follow up.

The people we support who were less able (scoring less than 25% on the skills assessment) generally moved from being largely disengaged to being engaged up to 50% of the time. At baseline, over 50% of this group were largely disengaged. At follow up, this had reduced to 27% with the remaining people engaged at least some of the time.

For only a relatively small number of people (10.5%) did engagement levels decrease.

**Skills**

75% of the people we support with severe learning disabilities showed increased skills in 2005/2006 compared with the 2000 baseline assessment.

The increase of skills of people with severe learning disabilities supports earlier findings [23] that enabling people to engage in meaningful activities, through the implementation of Person-centred Active Support, is associated with increased independence. This is particularly significant when we compare this with earlier research [24,25], which reported that following an initial increase in skills when moving from hospitals, people's skills do not continue to increase significantly in community settings.
CASE STUDY

Sheila’s story

Sheila, aged 53, has been living at a house supported by UR in Oldham for the last eight years. Before the introduction of Person-centred Active Support at the house, Sheila was largely disengaged. She was reluctant to go out of the house and would often not want to get washed or dressed. She lacked confidence and despite trying out different diets, was overweight. Her behaviour was often aggressive and challenging for staff.

Staff saw very little progress in Sheila’s level of engagement until they started actively adopting person-centred approaches. They introduced a morning routine and worked with Sheila to find out the things she was interested in, so she knew when to get up and had something to get up for.

They would knock on Sheila’s door once. If she didn’t get up they would go back every few minutes and knock again. Sheila reacted very angrily. But gradually she started to get up after only a few knocks. Now she gets herself up and washes, dresses and tidies every morning.

Sheila was clearly unhappy about her weight. Staff supported her to go to Weight Watchers but Sheila found the weigh-ins distressing, particularly on the weeks when her weight had increased. Staff tried a different approach and put together word and picture documents to help Sheila know which foods were good for her and which weren’t. They had their own weigh-ins, encouraging Sheila even if her weight had increased. Along with everyone else in the house, Sheila now puts together her own menu each week. She eats more healthily and staff are supporting her to go to keep fit classes.

As Sheila’s confidence has grown she has become more interested in taking part in activities outside of the house. Staff support her to go and see local shows and she enjoys karaoke nights and a drink at the local pub. She also has a paid job one day a week at the UR office in Oldham.

It is not only Sheila who has benefited from the introduction of Person-centred Active Support. There has also been a noticeable improvement in communication in the house and improved staff morale.
Person-centred Active Support

Support for 49% of the people we support was rated at over 67% on the Active Support Measure, compared to 29% in 2000.

There have been significant increases in Person-centred Active Support in the last five years. Person-centred Active Support scores increased in 60% of the services assessed in 2000 and the average score across all services assessed in 2005/2006 was 63%.

Scores on the Active Support Measure were divided into 3 categories representing poor (0 to 33% on Active Support Measure, mixed (34 to 66%) and good support (67 to 100%). A high score (“good support”) represents staff practices which appropriately facilitate and support engagement in meaningful activity and relationships, deal well with challenging behaviour and make use of written guidance and plans. 60% of people moved up within these categories. In 2000, only 29% of people were experiencing “good” active support. This increased to 49% in 2005/2006.

The analysis also showed that Person-centred Active Support had decreased for some people. This highlights the importance of maintaining the quality of support in services through ongoing training and management commitment. Preliminary analysis shows that practice leadership from front-line managers was important for improving the quality of staff support.

Communication

85% of staff report using and/or developing photos, pictures and objects of reference with the people they support.

A range of alternative communication methods are being used and/or developed in services. The number of alternative communications either in use or being developed in services increases as Person-centred Active Support scores increase and provides some evidence of the link between active support and the use of alternative communication strategies. This in turn provides some evidence that the integrated approach adopted by UR via the Way We Work Framework is effective.

Staff

Staff satisfaction is high and staff are clear about their roles. There is evidence that good management (i.e. how well the manager plans and communicates with staff) has a significant impact on staff satisfaction. 95% of staff report that they work well together. Team meetings, which focus on supporting people to engage in a range of activities, are held frequently.

Person-centred Active Support from staff. 17% of the most severely disabled people moved to being engaged for more than 50% of the time in 2005/2006.

Where Person-centred Active Support scores were low there is some change, especially for those with less severe disabilities, but this is not to the same extent as when Person-centred Active Support scores were high.

Engagement increased for all ability groups, but the biggest change was seen where active support scores were higher – here the percentage of people spending most of their time disengaged decreased from 30% to 1%.

Person-centred Active Support is particularly important for people with severe learning disabilities. For these people engagement and skills increased more when they were receiving
**Practice leadership**

An increase in scores on the Active Support Measure (leading to an increase in engagement) was strongly related to and predicted by whether or not front-line managers provided strong practice leadership. Particularly important was whether or not managers regularly observed and modelled good support to staff and whether or not they focused on engagement and Person-centred Active Support in team meetings and supervisions.

52% of staff reported that managers observe their practice monthly or more often and 54% say that observations are focused on involving the people we support in activities.

66% say that feedback from observations by managers is very/quite helpful.

Working with effective practice leaders was also linked to higher levels of job satisfaction for staff and better role clarity.

**Challenging behaviour**

32% of the people we support present at least one behaviour which severely challenges staff (14% had more than five behaviours rated as severely challenging).

People we support whose behaviour severely challenges staff were less engaged in activities and received lower levels of Person-centred Active Support. However, these people also tended to be the most severely disabled and although the presence of challenging behaviour was somewhat important in explaining lower levels of engagement, level of ability was much more important. The focus needs to be on ensuring that staff can work effectively with people of all levels of ability including those with challenging behaviour.
Implications for United Response (UR)

This project has provided valuable information for United Response both locally and nationally.

We have already used evidence from the project to implement changes and will continue to do so over the coming months.

Action already undertaken

Feedback and action planning were carried out straight after the visit to each service, allowing service staff and managers to implement many of the service specific developments and changes immediately. Follow up and additional support for these action plans continues via bi-monthly practice development forums.

We are currently updating corporate, divisional and area plans to reflect the national data collected and ensure that we continue to develop Person-centred Active Support in all services.

Additional resources are being developed and further work is being carried out to ensure that feedback (verbal and non-verbal) from the people we support is routinely collated. This is reviewed by staff teams to ensure support is matched to the individual’s needs and preferences.

We are developing a variety of approaches and tools to ensure good management and practice leadership are priorities for managers. In particular, additional support and training will be provided to assist managers and senior support workers to provide effective observation and feedback for staff, focused on how to actively support people to engage in a range of activities at home and in the community.

We are reviewing and developing organisational standards and training relating to challenging behaviour to enable staff to build on their knowledge, skills and confidence in supporting people whose behaviour severely challenges.

Future actions

We will continue to promote Person-centred Active Support through the Way We Work Framework. We will also provide additional training and information sharing opportunities for staff supporting people with severe learning disabilities and complex needs.
When we began this work in 1998, we were aware that although Active Support had been proven to have a number of benefits for the individuals we support, it had not had much impact beyond small pilot projects. Over the last five years we have demonstrated that it is possible for organisations to adopt a policy of person-centred approaches, including Active Support, and affect significant changes in the lives of people.

The development of a range of approaches including Person-centred Active Support, communication and positive behaviour support is vital to the development of person-centred approaches as put forward in Valuing People: A New Strategy for Learning Disability for the 21st Century [26]. It needs to be incorporated into the work practices of support providers and expectations of commissioners.

Organisations looking to take this step should bear in mind that the successful implementation of Person-centred Active Support requires people to approach their work differently, rather than just the introduction of new forms and procedures.

From our experience of the implementation process and from preliminary analyses of the data, practice leadership is extremely important. In particular, our experience has been that successful implementation is highly dependent on front-line leadership and management to:

- redefine how they identify and enable participation in a range of activities at home and in the community,
- recognise the value of routines in the lives of the people they support,
- ensure opportunities to participate are offered predictably and consistently,
- develop staff skills to support people in an enabling way,
- and monitor and respond to people’s verbal and non-verbal communication.

Managers need to incorporate performance management and practice leadership techniques into their work to ensure person centred goals and service aims are clear and are responded to as the primary objective.
Implications for research

Further research is needed to identify how to implement and maintain Person-centred Active Support. Key to this is the extent to which front-line managers provide practice leadership through direct teaching and coaching of their staff, and the impact this has on people.

Further research will look at the skills and support managers need to make this happen. It will also identify organisational factors and structures which promote the successful implementation and maintenance of Person-centred Active Support.

This study provides further evidence that the most important factor in determining the level of engagement in meaningful activity of the people we support, is that staff change the way they work with people to directly facilitate engagement, particularly for people who are the most severely disabled.
References


