

Creating an Ordinary Life
Active Support Project



Creating an Ordinary Life

Active Support and
Learning Disability

2012 - 2015



Department
of Health

the
active
SUPPORT
Project

ARC
England

Acknowledgements

We would like to thank the following for their support and encouragement:

The Department of Health

Members of the Active Support Advisory Group:

Sue Collingwood, NCHA

Julian Fennell, Mencap

Rose Gray, Autism Care UK

Gemma Grant, The Challenging Behaviour Foundation

Deborah Jenkinson, Derbyshire County Council,

Edwin Jones, Abertawe Bro Morgannwg University Health Board

Kathy Lowe, Abertawe Bro Morgannwg University Health Board

Gary Saunders, Department of Health

Andrea Wiggins, Avenues Group

Sarah Carberry, Avenues Group

Kelly Strouther, Perthyn

Staff, managers and service users at our project services in:

Allied Healthcare

Autism Care UK

Broadoak Group

CareTech

Chescombe Trust

Devon County Council

Edward Lloyd Trust

Flexible Support Options

Halas Homes

Life Opportunities Trust

Livability

Martha Trust

National Autistic Society

Nottingham Community Housing Association (NCHA)

Perthyn

Prospect Housing and Support

Prospects

Quality Care

Robert Owen Communities

Somerset Care

Contents

The Association for Real Change	Page 1
Creating an Ordinary Life - Active Support Project	Page 2
What do we mean by the term 'learning disability'?	Page 4
The history of Active Support	Page 5
Challenging Behaviour	Page 6
What is Active Support?	Page 8
Report:	
Year One - What we did.....	Page 10
Year Two - What we did	Page 16
Year Three - What we did	Page 20
Challenges and obstacles	Page 30
Conclusion	Page 31
Recommendations	Page 32
References	Page 33
Further reading	Page 35

The Association for Real Change exists to improve the quality of life for people who have a learning disability by supporting anyone who is involved in the planning or delivery of support and services.

The Association for Real Change (ARC)

Association for Real Change (ARC) is a leading umbrella body representing service providers in the learning disability sector.

We provide a range of services such as high quality information, networking opportunities, learning disability training, qualifications, publications, and Disclosure checks.

Association for Real Change is committed to promoting best practice within the learning disability sector and we work with others such as the Department of Health, Skills for Care, Big Lottery Fund and Comic Relief through a range of projects.

Association for Real Change works in England, Northern Ireland, Scotland and Wales.

ARC's Beliefs

- 1.** We believe that everyone should be treated equally and, as unique individuals, everyone makes valuable contributions to society.
- 2.** We believe that person centred values and models of support are the best way to improve people's quality of life.
- 3.** We believe that everyone should have the support they need to be included in their local community.
- 4.** We believe that people should have the opportunity to be involved in how their support is planned and delivered at both a local and national level.
- 5.** We believe that everyone who plans or delivers support should have access to the knowledge, experience and skills they need to continually improve what they do.
- 6.** We believe that people's quality of life can be improved by supporting those who plan and deliver support to work effectively in partnership with each other and with the people they support.
- 7.** We believe in the capacity of those who plan and deliver support to continually reflect and change their practice to improve what they do.
- 8.** We believe that people are best placed to make informed choices about how they live their lives.



Creating an Ordinary Life Active Support Project

Background

In March 2012 The Association for Real Change (ARC) made an application and was successful in securing funding from the Department of Health - Innovation, Excellence and Strategic Development Fund to run a three year project. The main focus of the project was improving long-term care and support for people with learning disabilities supported by a team of support staff.

The project would support teams to use methodologies of Active Support (AS).

The main aims of the project:

- Enable staff to engage people with a learning disability/autism and/or mental health to take a more active part in their own lives – at home in the community
- To build confidence and self esteem of people being supported as well as staff teams
- Maintaining current skills of people in services
- And an opportunity to learn new skills
- Improvement in health – (this would be an expectation of using methodologies of Active Support)
- Improvement in independence and choice making
- Reduction in behaviour that is challenging the service
- Reduction in staff support
- Reduction in staff turn over

The project commenced in April 2012. In total there were 30 services across England who registered on the project. All the services received tailored support for managers and care staff in Active Support practices.

The range of services registered on the project included those in: learning disability supported living services, enablement services, mental health, autism and day opportunity services.

After three years the project has been evaluated and documented. The outcomes reported in this document mirror much of the research relating to Active Support over the last 30 years.



What do we mean by the term 'learning disability'?

Mencap state that a learning disability is one of the most common forms of disability in the UK and go on to define learning disabilities as follows:

A learning disability is a lifelong disability acquired before, during or soon after birth and affects someone's ability to learn, communicate (which may be seen as behaviour that is challenging) or do everyday things. People with a learning disability find it harder to learn and understand. Some people need help with everyday tasks like getting dressed, eating, cooking, personal care, getting a job or social skills.

Other people with more severe or profound learning disabilities may require 24-hour care and support, particularly those with physical disabilities.

Complex Needs is the term applied to the range of multiple and additional needs that people with learning disabilities may have. This can include people with profound and multiple disabilities and people whose behaviour presents a challenge. However, people's needs are not fixed. They may develop more complex needs in later life or may display less behaviour that is seen as challenging once appropriate support is given. (Valuing People 2013). Individuals who have a label of learning disabilities

can and should be described in many other ways including, friend, neighbour, relative, colleague, community member, partner, employee, parent. A label describes one aspect of a person, but does not capture the whole person (BILD 2013).

For people with more complex needs, equality of access and opportunity usually means that specific adjustments need to be made and this may include very specialised support, which is commonly intensive and ongoing. However lack of understanding and aspiration about what can be achieved sometimes leads to an assumption that people will be passive recipients of care throughout their lives, as opposed to people who can make decisions and live as empowered citizens in our society. With the right support this is achievable.

It is important to understand that people with a learning disability are individuals with unique personalities, likes and dislikes, goals, and aspirations. Even people with the most profound learning disabilities can be engaged in the routines that make up everyday life. They will just need the right and effective support.

The history of Active Support

Certain principles of how to support and enhance the quality of life of people with learning disabilities have become widely recognised. Central to these are the notions of 'ordinary living' and the right to a lifestyle valued by society in general and these have been identified as:

- Being part of a community
- Having a network or relationships involving family and friends, having continuity in relationships
- Having opportunities to develop, have different experiences and develop competencies
- Having choices and control over life
- Being given status and respect and
- Being treated as an individual

(Welsh Centre for Learning Disabilities, 1996 Schalock et al 2002)

Central to these outcomes is the day to day experience of people in services. Personal development is achievable if people take part in activities which broaden their experiences, develop new skills and even have an opportunity to try something new. Relationships depend on meeting people and interacting with people which contributes to having an ordinary life (Bellamy et al 1990). The same would apply to the other list of values or outcomes above including the four principles – rights, independence, inclusion and choice from the 2001 White Paper Valuing People (Department of Health 2001). The only way these outcomes can be achieved for people with learning disabilities is to have support

from a skilled workforce who understand person centred approaches.

In the 1980's as Governments began to endorse programmes of support that would better promote people to have an ordinary life and move out from the Institutions and long stay hospitals. It was presumed that people's lives would automatically improve simply by living in a smaller home in the community. For some people, these improvements did happen, but for others nothing much changed. They were still disengaged from the activities that make up an ordinary life.

(It must be remembered that disengagement is not the ability or inability of the person, but is contingent on the skill and motivation of the staff team to engage and support the person in the right way. Equally importantly, the skill and motivation of the staff team is contingent on having a manager/team leader or practice leader with the right motivation and skills to support their team).

Research continues to show that most of the day to day activities in both residential and supported living services are being undertaken by support staff, especially for people with more complex needs, with the people being supported frequently spending hours at a time disengaged with no focus or interaction. Their lives do not resemble anything like an "ordinary life".

Challenging Behaviour

Some people with learning disabilities can display behaviour that is challenging and huge amounts of money are expended (by both health and social services departments purchasing or funding), on forms of accommodation that are designed to contain and control behaviour. Professor Jim Mansell's report ('Services for people with Learning Disabilities and Challenging Behaviour or Mental Health Needs' 2008) was particularly clear that the cause of challenging behaviour most commonly lies at the door of poor services that fail to adequately engage people in its service in activities that make up daily life.

Mansell noted that:

- the dominant model of support in services for people with learning disabilities is relatively unskilled caring and 'minding'.
- environmental risk factors (such as poorly organised and trained staff) are widespread among services
- the evidence found that staff do not generally interact with the people they support in a way that enables the person to achieve greater levels of independence participation or integration.
- the amount of support received by the person is relatively low (about 9 minutes in every hour) and facilitative assistance much less (1-4 minutes an hour on average).

- where individuals with problems are cared for in environments that do not respond well to their needs, challenging behaviour is likely to develop and remain in the person's repertoire.

('Services for people with Learning Disabilities and Challenging Behaviour or Mental Health Needs' 2008)

A central premise is that most typical members of society with or without a learning disability spend most of their time participating in various types of activities throughout their day. Some activities are more motivational than others, some easier. Having a variety of activities and responsibilities make our lives ordinary and balanced. People with learning disabilities especially people with more profound learning disabilities will need support to do most of these ordinary activities which may take place at home in the community or by building friendships, relationships, getting a job etc.

Taking part in activities is the basis for personal growth and development, an opportunity to form new relationships, increase social inclusion, education/work and independence. Sometimes staff think that the people they work with do not have the right skills to do an activity or feel a need to undertake these activities themselves. Hence the person being supported is not involved in their own lives.

Active Support changes the mind set of support. Staff begin to see everything in life as an activity or an opportunity for a person to take part. They begin to look at activities as having steps and each step is as important as the other. Just being able to do one step is an achievement.

The move to identify models that increased engagement and involvement for people with learning disabilities began in a project in Andover (England) (Mansell et al, 1987b). In 1987, the method of support that began in Andover was first defined as 'active support' (Brown, Toogood and Brown, 1987; Jones et al, 1996; Mansell et al, 2005)

Active Support is still one of the most researched areas relating to people with learning disabilities that conclusively demonstrates, that where staff used the tools and methodologies inherent in Active



Support, people do have a better quality of life.

(Felce et al 1986; Mansell and Perry 1994; Thompson et al 1996; Jones et al 1999; Fence et al; Mansell et al 2003, 2008; Sancliff et al 2007).

Results taken from United Response 2006

'The results show that person-centred approaches have resulted in the people supported by United Response being significantly more engaged in everyday activities, with the greatest change being seen among people with the most complex needs. 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%'

(Developing person-centred approaches so that people can be more included, Bev Ashman Dr. Julie Beadle Brown 2006).

What is Active

Active support is a methodology of support that is person-centred. It provides structures and routines that increase opportunities for people with learning disabilities to engage in age-appropriate activities that make up an ordinary life. Active Support provides people with support that is commensurate with their abilities. The methodologies of Active Support are applicable to all support settings, not just people with learning disabilities.

Active Support is a proactive strategy for reducing behaviour that challenges. Where Positive Behaviour Support is delivered in services its effective implementation is dependent on a number of service characteristics that are inherent within Active Support methodologies. (Mansell et al 2005)

Person Centred Planning and Person Centred Action

In 2001 the Department of Health published a new White Paper (Valuing People) that set out a strategy for the development and delivery of health and social care services for people with learning disabilities in England. A central component of this strategy was to introduce Person-centred Planning (PCP) as a means of increasing the extent to which supports were tailored to the needs and aspirations of people with learning disabilities. This strategy is also prominent in the Welsh Policy review (Fulfilling the Promises, 2002), the Welsh Government's Service Principles and Service Responses (LDIAG, 2001 and WAG, 2004) and the Scottish The Same as You (Scotland Department of Health 2000).

PCP is a tool for services to find ways of listening to people to find out what is most important to them and what they want from their lives. However, some people may not be able to say what they want and may need support from families, friends and people who know them well. At the core of successful PCP is working with people to help them identify and achieve the things they want to do, need to do or have to do so that they have an ordinary life. Done well, PCP gives a sense of longer-term direction in a person's life and provides the bigger picture about what the person wants. The service then needs to support the person achieve the plan. **Active Support enables this to happen.**

One of the problems is that, although an increasing number of people with learning disabilities now have a Person Centred Plan, staff can and do struggle to turn these plans into action, particularly for people with profound learning disabilities. However, because Active Support is based upon the individual needs, abilities and potential abilities of each person, it is fundamentally person-centred in its approach. It shows staff how to adapt their behaviour to work with each person they support as unique.

Active Support works successfully as a stand-alone approach and, where pertinent, works successfully when used concurrently alongside PCP, positive behaviour support (PBS) and total communication. Active Support enables teams to turn planning into action, so enabling positive and measurable outcomes.

Active support is a methodology of support that is person-centred. It provides structures and routines that increase opportunities for people with learning disabilities to engage in age-appropriate activities that make up an ordinary life.



Year One: What we did

Project outputs Year One

- April 2012 project recruited one manager, two coordinators and an administrator.
- Five presentations were delivered.
- Yahoo email communication set up.
- Advisory Group established.
- Ten services registered onto the project from the East and West Midlands.
- Education and coaching delivered to project services.
- Project services registered onto the E-Forum.
- Two newsletters compiled and delivered (the second one having contributions from the services discussing emerging progress).
- A further 20 services recruited from across England for the project.
- 160 staff in total attended support session for Active Support in Year One.
- A total of 80 clients were involved in the ten services for year one.

November 2012 the project recruited ten services who would be the pilot services for the project and came from:

- Supported living
- Day opportunities
- Mental health services
- Targeted support.

The services supported people with a range of learning disabilities including profound and multiple disabilities and or autism, mental health and/or dementia.

Advisory Group

Support for the project was provided by an Advisory Group which included representation from specialist providers' services, academics working in the field of positive behaviour support and active support, commissioners, family representative and representation from the Department of Health. The Advisory Group met twice a year throughout the three years of the project.

Presentations

The project undertook five presentations across England to promote the Creating an Ordinary Life Project. The presentation discussed Active Support, what the project involved, the commitment, what the outcomes of the project were and what each service would have commit to.

It was also discussed that the project would be an opportunity to take forward Active

Support after the project had finished and that the provision of the 'training' and the support should only ever be seen as part of the process of Active Support. Research shows that in order for Active Support to be successful in an organisation it has to become organisational culture. This would include Active Support being:

- integral at strategic operational and tactical levels
- integral to outcome monitoring systems
- incorporated into business plans
- included in policies and procedures
- mandatory for all management and staff training
- integral to organisational monitoring and reviewing processes
- become part of supervision and appraisal processes
- become part of staff induction and probation - looking at skills
- being linked into all other training.

The project would also be an opportunity for services to feed back strategically regarding areas that may need to be developed should they decide to implement Active Support throughout their organisation.

The presentations provided an opportunity to gain feedback of current views of Active Support - some of the comments included:

- services felt that they were already delivering the model of Active Support and just needed to refocus their support

- none of the services had attended any previous Active Support tuition
- managers did not always have time to coach and mentor staff in the service relating to Active Support
- most services relied heavily on paperwork
- none of the services had Active Support or experienced Active Support practitioners in their workplace or organisation
- most services relied on current training
- all services said that everyone had a PCP or were working towards one
- managers did say that they tell staff what they needed to do but it was not always happening.

December/January 2012/2013

Ten services received tailored support for their staff team and their manager on Active Support. The overview of the day was:

- History of Active Support
- What Active Support is
- What it looks like in practice
- How to do it
- Basic monitoring systems to evaluate what the team are doing
- How you will be supported to do it!

Staff enjoyed the session and gained a lot of understanding, with comments being very positive. Some of the staff comments about what they enjoyed follow:

- *“I really enjoyed participating with activities. DVD’s were an eye opener.”*
- *“The paperwork, information and step by step activities.”*
- *“The knowledge of the trainer.”*
- *“The content of the course, ideas from the paperwork and the interaction from the group.”*
- *“Assisting the service user to live an ordinary life.”*

The main concerns staff were:

- *“Most people we work with are not on a 1-1 so it would be really difficult to do.”*
- *“We already have loads of paperwork to do and my manager says I need to be with the service users more.”*
- *“There is not enough staff somebody always calls in sick.”*
- *“People we work with have profound multiple and physical disabilities.”*

- *“There is not enough time in a day to do everything.”*
- *“It’s too risky to use kettles, irons and knives, etc.”*
- *“It’s a persons choice to do what they want they are adults.”*

Research continues to shows that more staff does not equal better engagement (Dr Julie Beadle Brown).

A second day’s theory and coaching was delivered to managers/team leaders. The theory day discussed the role of the manager and emphasised the paramount importance of their responsibility to ensure that Active Support was delivered in their service.

Support was given to managers in using the newly acquired Active Support tools in a practical application in their workplace. Both days were thought provoking. All managers could see the importance of the role of coaching, especially when looking at staff behaviour change.

There were few concerns from managers regarding this session. Discussions were generally around:

- Finding time to deliver coaching
- Having the confidence and skills to coach staff found the role play (after their initial terror) and the paperwork was very useful especially when linking into supervision and performance management.

Newsletter

Each service during year one contributed a news article for the Creating an Ordinary Life newsletters^{1,2}. Their articles described how the project was developing within their service and what the emerging outcomes were. Commitments were made that further articles would be contributed in year two and three.

Support from the Project

Telephone support was given to the contact person for each service throughout the three years. The service could also contact the project coordinators to ask for advice at any time. There were also opportunities for the coordinators to attend team meetings via Skype to support with barriers if requested.

Measuring the outcomes

Outcomes were evaluated by a range of measures: anecdotal evidence, observation by members of the team, word of mouth, professionals and senior managers within the pilot organisation, service managers support staff and families. Feedback from service users was done by 1-1 discussions with staff and fed back into the newsletters.

Outcomes from the pilot services year one

The following quotes are taken from the newsletters from services in year one. The services reflected on how Active Support was impacting on their service and teams, and how the implementation of the Active Support approach was progressing within their service.

1. <http://arcuk.org.uk/wp-content/uploads/2015/04/CaOL-Newsletter-Issue-1-Oct-2012.pdf>

2. <http://arcuk.org.uk/wp-content/uploads/2015/04/CaOL-Newsletter-Issue-2->

- *“We have found that Active Support is a great tool.”*
- *“Active Support has revolutionised the way we support people.”*
- *“The staff teams are more confident in developing the skills of the people we support.”*
- *“We are a very different service to what we were a year ago.”*
- *“Active Support is really helping the staff to support people more. One service user that it did help with was D. D needed support to put his own catheter bag on – he now puts it on himself. D really takes pride in it and tells staff when he has done it.”*
- *“We have definitely noticed a big change in attitude from staff. Service users want to do more.”*
- *“We have changed many times over the last year and adapted the way we record service user’s engagement (usually to respond to commissioners requests for data). During our ‘team day’ we decided to have small working groups to look at service user’s plans and support (active support) to encourage service users who have been hard to engage in activities. The aim will be to develop a plan which supports service users in the way they want to be supported as well as a way which encourages their responsibility.”*
- *“One service user who had previously not gone out with staff enjoyed the Christmas market and now goes out once a week for coffee and a browse around the local shops with staff.”*
- *“On a recent visit to the Service the Manager told me how one service user had spoken a complete sentence for the first time in years.”*
- *“DR would always wait to be asked to have his shower and the staff would go and assist with the personal care now DR will get up and go and shower himself without staff assistance and with no prompts at all.”*

- *"In the beginning, some staff were reluctant for change, although there were some staff who actually felt quite upset as they realised that they were doing far too much for people and potentially de-skilling them."*
 - *"There was initial resistance and the manager has admitted that she was very cynical but she was prepared to give it a go. The introduction of Active Support and systems and paperwork to support it quickly brought about benefits and the staff and the manager became very positive about it"*
 - *"We noticed staff tended to do most of the activity. This has now changed. The people we support are now fully involved from shopping to food preparation, to cooking and cleaning. People we support are now taking part in vehicle checks and putting petrol in the car."*
 - *"Staff started to take on board that they were not responsible for doing things for people and their role was to enable tenants."*
 - *"Staff are using hand-on-hand techniques and guiding to enable service users to develop skills and confidence to take more of a role in everything."*
 - *One gentleman was not buttering his own toast independently, with encouragement he now is and was so proud that he got all the staff to look at what he had achieved."*
 - *"And what a difference we are beginning to see. As a Mental Health service I wanted to include Active Support with the principles of Recovery Star (World Health Organisation) and have developed the participation record around the recovery star."*
- "One lady will now peel potatoes for tea completely independently and on one occasion informed me that she was going to do them on her own because the staff were busy and she was fed up of waiting."*

Year Two: What we did

Project outputs Year Two

- Continued to support via email and telephone.
- Delivered support to staff and managers from a further 20 services who supported 320 staff supporting 160 Service users.
- Two advisory meetings held.
- Two newsletters produced.
- Each service visited for 1-1 support where required.
- Conference for Year Three planned.

The following quotes are taken from the newsletters for services in year two ^(3,4). They were asked to reflect on how Active Support was impacting on their service and teams, and how the implementation of the Active Support approach was progressing within their service.

Reviews from services - outcomes

- *“Over the past 9 months, the project has had a magnificent impact on one individual’s quality and standard of living. Working closely with a tailored pathway, it gave his identified outcomes clarity and structure that ensured that he could have a real sense of achievement.*

“At the start of the project he wanted the opportunity to travel independently, allowing him to feel a part of the wider community. Working with the individual, support staff were able to break down the task into manageable segments - for example; assessing the foundation skills like being able to read a bus timetable; being able to locate the bus station using local knowledge;



knowing where he had to get off the bus; understanding what to do if he missed the correct bus stop, etc. As the individual progressed through each stage, the level of support was adjusted accordingly until he achieved his goal of travelling independently.”

“As a result of this newly found independence, the individual asked to extend his goal to find employment. To achieve this the same Active Support process was followed with the end target broken down into manageable segments, beginning with understanding employment; building a CV; becoming familiar with the application process.

3. <http://arcuk.org.uk/wp-content/uploads/2015/04/CaOL-Newsletter-Issue-3-Oct-2013.pdf>
4. <http://arcuk.org.uk/wp-content/uploads/2015/04/CaOL-Newsletter-Issue-4-May-2014.pdf>

- “The journey of finding employment allowed the individual to discover many things about himself, and allowed him to develop a more realistic view of life that expanded his horizons. Through the project staff gained skills to support him to gain the confidence to try new experiences; this led to him becoming a volunteer for a conservation project. This successful volunteering position enhanced his personal development; increasing his confidence in his abilities enabling him to take on a voluntary position in a local café where he worked towards his Health and Safety in the Workplace – Level 2.”*
- *“There has been a benefit to the staff teams too in that they are more confident in developing the skills of the people we support, more able to look for creative opportunities for greater independence and able to ‘take a back seat’ where required!”*
 - *“I knew that we provided safe and good care but also that it was out of date and didn’t capitalise on all the opportunities for the people we support to have independence and involvement. Active Support has allowed us to achieve this and I believe that the difference in the way we conduct our business now has allowed our reputation to grow with external professionals who visit our service. I feel we have a service we can now be proud of and can genuinely market as person centred - rather than just paying lip service to the principles, we actually do it!”*
 - *“People who were sceptical at the start have seen the proof of the positives and have embraced the changes and celebrated the achievements together. I believe it has brought the staff team together and made them think more about the support each individual needs to facilitate their engagement in their own lives.”*

Project reviews: Year Two

Positive Outcomes

There have been some real and positive outcomes from the services. Services are beginning to feel more confident with their support feedback and adaptations. Below are samples:

- *“People being supported are engaged more”.*
- *“Self esteem and confidence continues to build for people we are supporting and staff!”*
- *“Teams are reporting that they realise that even the small ‘things’ in life are a great achievement for someone with a learning disability especially for someone with a more profound learning disability, eg, opening your own curtains making a meal or just taking part in that meal.”*
- *“Staff are considering areas around sensory needs of people thinking more about communication and the environment.”*
- *“As people do more they are able to choose what they want to do.”*

Barriers during year one and year two

Staff Turn Over – Staff turn over, vacant posts and sickness continued to impact on the project. This did result in poor correspondence and therefore more time spent gaining feedback. Staff turn over and sickness also impacted on service delivery.

Managers’ Time

Some managers were finding it difficult to spend time in the service as other ‘priorities’ of running the service had to take over and in many cases was happening more and more. Coaching and mentoring will be overlooked when this happens.

Risk Management

Some staff were risk averse and needed extra support from their manager. This tended to be more in services where the organisation itself was risk averse or risk was not always seen as an outcome for having an ordinary life. Risk was at times disabling rather than enabling.

Year Three: What we did

Project outputs Year Three

- Continued support for all services via telephone, email and Skype.
- Further visit to meet with service managers to gather qualitative outcomes.
- Arranged, promoted and delivered Creating an Ordinary Life – Active Support Conference.
- Production of booklet for parents, carers and service users (easy read).
- Production of two newsletters.
- Two Advisory Group meetings.
- Active Support training materials rewritten in light of project experience.
- Further promotion of the Active Support Handbook.
- Prepared exit strategy.
- Prepared concluding report.

Guidance

Active Support has been talked about for over 30 years. Services now have all the policies and procedures in place. Websites say they are involving people to have an ordinary life but the evidence continues to show that sometimes it can be tokenistic and is not always happening in practice. We therefore decided to write a short guide⁵ to help parents not only ask the right questions when they are looking for a good service but more importantly what they should be able to see when they go into a service.

We have also developed a short easy read guide for people with learning disabilities.⁶

Active Support Distance Learning Pack

For support teams who want to achieve a knowledge based qualification on Active Support there are QCF based distance learning materials available from ARC.⁷

Active Support Handbook

The Active Support Handbook was originally written in 1996 by, Edwin Jones, Jonathan Perry, Kathy Lowe, David Allen, Sandy Too-good, David Felce and Judith Jenkins.

The Handbook started as a series of booklets. The booklets have since been combined into a single Handbook (free to download from the ARC Website⁸) - a useful resource for organisations, managers and staff to recap on training, or for people to just read about what Active Support is.

The Creating an Ordinary Life Conference

The conference took place in September 2014 in Cardiff. Over 150 people attended, with a cross section of representation from:

- Behaviour managers and practitioners
- Day Care officers
- Area and Regional managers
- Training and support managers
- Directors
- Locality and Service managers
- Support staff
- Operation directors
- Research and service development managers
- Service development consultants
- Office managers
- Trustees
- Personalisation coordinators
- Senior business managers

The morning sessions focused on what was currently happening in Active Support, linking in with outcomes, work in dementia services, behaviour that is challenging and a session on the importance of Manager as Coach. The afternoon was set aside for three organisations registered on the project to feedback on how the project had made an impact on their services. The final session was an open discussion for delegates to ask the panel questions.

Presentations from the conference can be found on the ARC Website.⁹

5. <http://arcuk.org.uk/activesupport/files/2015/04/What-is-Active-Support-Parents-Family-Carers.pdf>

6. <http://arcuk.org.uk/activesupport/files/2015/04/What-is-Active-Support-Easyread.pdf>

7. <http://arcuk.org.uk/publications/shop/active-support-active-support/>

8. <http://arcuk.org.uk/activesupport/files/2014/09/Active-Support-Handbook-revised.pdf>

9. <http://arcuk.org.uk/blog/active-support-creating-an-ordinary-life-conference-presentations/>

Review from year three: Outcomes

The following quotes are from services in year three. They have reflected on how Active Support was impacting on their service team and people they support. The full articles can be seen on the ARC Website at: <http://arcuk.org.uk/activesupport/category/reviews-from-pilot-services-2015/>

- *“Active support has provided the service users with opportunities that may have not previously been offered. This is in all aspects of their lives, from daily living tasks to community and recreational activity.”*
- *“Previously one of our service users did not go out, through choice, at all. Using participation records, it was evidenced that the level of engagement was very little. Staff took it upon themselves to create opportunity plans to help develop his confidence and skills. The participation record also evidenced to health professionals his level of engagement and as a consequence enabled a change of medication. Since Active Support and the medication change this person has been out into the community after four years confining himself to his home.*
- *“He makes regular visits to communal areas and attends parties in our communal hall, which at one time he would have declined. Negative behaviours have since reduced and this has been noticed not only by staff but also family and health professionals.”*
- *“Our residents have become more involved in their health in terms of remembering what appointment they may have coming up and who they may need to speak to if they have any health issues.”*
- *“As M had never been instructed or shown how to carry out simple tasks H started with very tiny steps with lots of verbal and physical prompting. M was shown how to load the dishwasher then asked to put his cup in the dishwasher. Eventually M was not only putting his cup in the dishwasher but loading it after dinner, putting the powder in and even turning it on. Now after 8 or 9 months, H will ask M: “M, can you load the dishwasher please” and that is the only prompt that he needs.*

“M has been with us for 10 months and since he came he is a different person. His personal care has improved, had a haircut, been on holiday, been to the pub etc. and we have seen what a lovely gentleman he is, very placid and easy going not at all like his risk assessment stated.

- “People we support are more confident and want to do more. In many cases they have always been able to do more, we just did not always give the person an opportunity to do it! One person has had a significant reduction in weight loss as they are now walking more and supported to think about what they are eating. Looking at more informed choice.”*
- “She now regularly uses the phone to let us know that she is on her way home from her work placement giving her a sense of security. She has privacy when making or taking her phone calls as she can now use her own phone in her bedroom. It has given her greater independence and more privacy and she feels ‘normal’ (like*

every other young person) as she has her own phone and she has a sense of achievement because she can do it all by herself now.”

- “The Senior Management Team were completing Progress for Providers and as part of this process realised that culture was an issue in enabling us to provide truly person-centred support. The Edward Lloyd Trust had and has fantastic staff that were very caring and known for going extra mile. We regarded the support we provided as being person-centred but it did not appear to be very enabling and was very much based on a caring or ‘hotel model’ of support. In embarking on a journey to change culture we were clear we did not just want training for staff, we wanted something which would support us to embed a different culture of support which was enabling and facilitated growth and learning for staff and the people we support. We wanted this type of support to be embedded so that it was quite simply ‘The way we do things’.*

“We explored a number of options and felt that the values of Active Support were a good fit with the values of the Trust which we had just refreshed during the business planning process.”

- *“Through the training process the majority of staff were open to the way of working introduced to them but there was some opposition e.g. it won’t work with the person I support, it won’t work with people with complex disabilities or children’s services. However as managers began to implement Active Support in services and staff began to see the benefits for them and for the people we support there has been less resistance and the majority of staff are very positive about it and like to share stories of how the people they support have become more engaged with their lives and we have some fantastic examples:*
 - *A house with 2 young women with very complex disabilities are now more engaged in their personal care in relatively simple ways such as carrying*
 - *the towel on their knee in the wheel chair.*
 - *Many examples of people being more involved with domestic tasks in the house*
 - *One young woman we support has lost over a stone in weight by being supported to attend a slimming class and cooking and preparing her own meals.*
 - *A woman we support with challenging behaviour is being supported to be more involved in doing her shopping and is swiping her goods through the self-scanner with support.*
 - *A gentleman we support who is profoundly disabled is now able to feed himself small things such as sweets.*
 - *Staff have developed an opportunity plan for the women we support with the aim of enabling her to do her own washing. Much to their surprise they discovered she could do it and always had been able to but because we had been providing a ‘hotel’ model of support she had always let staff do this activity.”*

“Staff attitudes are different now. We tended before to be more staff focused than person centred focus. Support before the Project was good but now it’s great. We are working ‘with’ a person more now rather than ‘for’ a person. People are working together.”

- *“Joe’s behaviours decreased as communication skills improved and Joe and his support staff began to understand each other and communicate effectively. Joe’s confidence has also improved and he has begun to involve himself more around the house and actively taking part in tasks with very little prompts. He has been enabled to participate in a wider range of activities within his community.*

Overall Active Support has really benefited Joe in all aspects of his life. This summer he was supported to attend the Tour de France in Yorkshire and it really has enhanced the quality of his life. All of the gentlemen in the house are more engaged in their own lives and are actively involved in aspects of day to day activities in their home and are more active on the community.”

- “I would just want to say that I have noticed a huge improvement in Amy’s communication skills and engagement in the music. I have worked with Amy for about 5 years now and difference recently is incredible and really wonderful to see. I can only attribute this to her support staff. Her sentence formation and vocabulary has improved so much that she now engages in short conversations and can answer a simple question. It is a joy to see and experience this as her tutor. She appears to be so happy and confident now.”*

Adult Learning Alliance Tutor
- “One of the staff teams had a period of Interactive Coaching as part of an Active Support project by the Newcastle BAIT Team (Behavioural Analysis and Intervention Team) to further develop the support they provided to Simon. This coincided with us implementing Active Support. In their report they commented that:*

“It was a pleasure for us to work with the team. Before training staff were on-task 52% of the time and Simon was engaged 30% of the time. During the second activity observed, staff were on-task 83% of the time and Simon was engaged 45% of the time. This means Simon’s participation rose by a third, and staff on-task behaviour by over half”
- “During the course of the project Mr J has decreased the amount of medication that he takes & Mr D has improved oral hygiene.”*
- “Many care managers have commented on the changes in the service users and their abilities to undertake tasks around the home and parents have noticed that when their dependents go home they are more inclined to help around the house. Indirectly there have been improvements in service users’ wellbeing and alertness. They have been more engaged in day to day life activities and there has been a reduction in some of the aspects of challenging behaviours that were being displayed. Possibly due to reduced boredom and increased self esteem”*

- *“Staff have also been much more conscious of the language that they are using with people. I do not think people realised how their use of language impacts on a person’s interpretation and understanding. Staff have been more aware of terminology they are using, and been more aware of not “flowering up” instructions. Instead clear, precise and direct communication and instruction is being more widely used.”*
- *“One service user has made some dramatic changes in his life. He is now, with support, able to clean his bedroom, make his bed, feed his fish, run his bath, and use a tablet to play games and look at the internet. On a recent check up with the dentist this gentleman was congratulated on his oral hygiene which is an aspect of his personal health he now undertakes with support. He is happier, more alert and more engaged with others since joining our service.”*
- *“We have had some very positive comments from parents, carers, local authority and commissioners on the support provided by our service since the implementation of Active Support.”*
- *“We have a new fully furnished training flat which opened last summer. In the training flat we are able to provide 1:1 support to customers and focus on independent living skills. We organised a grand opening and invited other professionals we work with, parents, carers and anyone else who maybe interested in our service. At the event we had customers and staff demonstrating active support, task analysis and outcome star reviewing. We received lots of praise and even made it to the local press. From this event we have gained links with the local secondary school SENCO facilitator who would like to use our facility.”*
- *“Physically putting Active Support into practice has been great. Staff quickly adopted the principles and this has been evident in the working environment. Staff have*

been standing back rather than jumping straight in and doing a task for people. One example was a lady who always asked for her orange to be peeled. A staff member used this as an opportunity to provide Active Support by starting her off with peeling each bit, she gradually did a little bit more each time for herself. Customers at lunch times have been doing more for themselves and staff have worked with individuals who would normally expect their lunches to be prepared for them."

- *"Previously staff tended to focus on outcomes rather than on the inputs to achieve the outcomes. For example, a fence had to be repaired so that is what the staff would focus on and people being supported would just observe the fence being repaired. Staff did not see how they could get the job done as well as support people to take part in the process of fixing the fence. Active Support helped staff to be reminded what their job role was, ie supporting people to run the farm."*

- *"Through effective planning, a scheme of work was produced, based on the Active Support paperwork. We combined this with the person's person centred plan and review literature. This became a quick and effective reporting system which provided the management with a precise tool for measuring the depth of outcome which was able to communicate in a definitive manner to commissioners and circles of support.*
- *"Active Support has been strengthened by reports and observations carried out by Occupational Therapists, Speech and Language Teams Social Workers and Commissioners. Families were at one time a little negative and did not feel involved. Now staff are involving them and communicating families feel more involved with SALT ABI therapists and the whole team in general."*



The Challenges and Obstacles

Releasing staff teams:

It is very difficult for entire staff teams to be released simultaneously for a day's training, but if Active Support is to be successful it requires that every member of the team be trained. A stipulation of the training was that teams needed to be trained with as small an interval between training days as possible.

Reluctance to change

Some service providers, staff and relatives found the concept of Active Support challenging. It can be difficult for people to see that the Hotel Model is not an empowering model or how modern services should provide support. Other factors that negatively influenced a reluctance to change was inertia, comfort with existing methods, perceived time pressures, lack of motivation and management support and feedback.

Some of the education and coaching sessions were spent challenging these beliefs and re-focusing staff to the fundamental values and attitudes that should underpin the provision of good support.

Staff turn over and sickness

Staff turnover continues to be a barrier to improving services and consistency. In Year One, one service had a 50% staff turnover. A number of the projects had managers changing job roles and either leaving the organisation or moving out of the sector. This impacted on the team if the new manager did not have an understanding of Active Support. Staff sickness and rota vacancies also impacted on the Project.

Some managers left the service or were promoted with new managers not having an understanding of Active Support. This had implications for the Project. (Currently Active Support is not a mandatory programme for newly in-post support staff or managers).

Lack of leadership and management skills

We have already seen that where services are managed and led by excellent managers the team will be better supported, develop better skills and interactions with the people they are supporting. At times there was a lack of leadership, especially coaching and mentoring which impacts on staff behaviour. Managers are beginning to gain more confidence in these areas.

Organisational Culture

Some teams found it difficult to work together or there was organisational conflict. The Project regularly communicated via telephone to try and keep teams focused.

Organisational Requirements

With the pressures of austerity and greater expectations to do more with less it was sometimes difficult to maintain contact with key people on the Project.

Recording Systems

Although there was a lot of emphasis from services on recording, much of it currently emphasised compliance, which is necessary but there was little paperwork showing quality of life.

Conclusion

The project has enabled services to make significant impact on the lives of people being supported by their service. The outcomes of the project have been met in most areas and it has been shown that there has been an improvement in:

Reductions in behaviour that is challenging

People are being supported to take part more in their everyday lives by staff changing their behaviour and delivering a more person centred model of support.

Improvements in mental health

People are increasing their self esteem and confidence and are just 'doing' more in their own lives supported by staff who have changed their support to focusing on what a person needs to do and wants to do to. People are more occupied throughout the day.

Improvements in oral hygiene

Managers have reported that people in their services are having less dentistry work carried out and dentists are commenting on the improvement in oral hygiene.

People developing new skills by taking part in routine activities

Some people have learnt to catch a bus independently for the first time; some are being supported to get a part time job; some are developing skills in animal husbandry; some engaging in work experience.

People are maintaining current skills

Staff give people opportunities to 'do' what they can already do regularly.

People with complex and profound learning disabilities are involved in their own lives more

Staff are "working with" rather than "for". The time people are disengaged has been reduced.

Reduction in support

This has been achieved by staff giving just the right amount of support, and encouraging the person to do more. Enabling skill development motivation and self esteem.

Health Improvements

Services have reported that health has improved in the following areas:

- Reduction in the intake of alcohol
- Reduction in smoking
- Reduction in medication for mental health
- Improvement in oral hygiene
- Weight loss - healthier eating and exercising

Staff Turnover

Evidence for reduction in staff turnover has not been able to be calculated over the short duration of the project. Research undertaken by the Avenues Group in Kent however showed a propensity to leave by staff decreased from 34% to 10% where Active Support had been implemented. It is hoped as staff feel more valued and are supported to learn new skills by a good manager, staff turnover will reduce. Further research is required in this area.

Recommendations

- Include Active Support in policies and strategies at all levels.
- Services should describe the functional activities they offer as well as their basic elements of provision (buildings, staff resources etc). This will help stakeholders to see what peoples lives 'look' like on a day to day basis. This will enable services to be commissioned on what they deliver and not what they say. They should clearly be able to demonstrate evidence based practice and how this is achieved on a day to day basis through Active Support methodologies.
- Health Education England, Skills for Care and Skills for Health to work in partnership with people who need care and support, parents and carers to develop evidence based learning. Such programmes must be monitored and delivered by professional and competent skilled facilitators.
- Active Support and staff skill development should link in with the induction process and on going supervision and appraisal system.
- There should be a robust system in place for monitoring the outcomes set out in the initial plans, (PCP) which must include Quality of Life. Monitoring systems must not be reliant on a paper based system alone.
- Managers of services become competent and knowledgeable in both Active Support, coaching and mentoring to develop their team. Time must be given to managers to deliver this role in practice. Active Support has to be driven by the manager for sustained implementation.
- Further research to be undertaken into the many health areas that could profoundly influence and improve peoples' lives.

Christine Rose

Project Manager

March 2015

References

J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, *Challenging Behaviour: a unified approach* (2007)

Winterbourne View Time for Change: transforming the commissioning of services for people with learning disabilities and/or autism

Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

Ashman B and Beadle Brown – *A valued life developing person centred approaches so people can be more included* (2006)

Stancliffe, R. J., Harman, A., Toogood, S. and McVilly, K. R. (2007) *Australian implementation and evaluation of active support*. *Journal of Applied Research in Intellectual Disabilities*,

Department of Human Services. (2008) *Evaluation: Person Centred Active Support in Rural Victoria*. Melbourne. Department of Human Services.

Totsika, V., Toogood, S. and Hastings, R. (2008) *Active Support: Development, Evidence Base, and Future Directions*. In L. M. Glidden (Ed

Stancliffe, R. J., Jones, E., Mansell, J. and Lowe, K. (in press) *Active Support: A Critical Review and Commentary*.

Jones E, Felce D, Lowe K, Bowley C (2001) *Evaluation of the dissemination of active support training and training trainers*

Felce D, Jones E, Lowe K, Perry J. (2003) *Rational resourcing and productivity: Relationship among staff input, resident characteristics and group home quality*.

Jones, E. and K. Lowe (2005) *Empowering Service Users Through Active Support in Patricia O'Brien & Martin Sullivan Eds Allies In Emancipation: Shifting From "Giving Service To Providing Support" Melbourne*.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K. & James, W. *Challenging Behaviours: Prevalence and Topographies*.

Lowe, K., Jones, E., Allen, D., Davies, D., James, W., Doyle, T., Andrew, J., Kaye, N., Jones, S., Brophy, S. & Moore, K.. (2007) *Staff training in Positive Behaviour Support: impact on attitudes and knowledge*.

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Strong, G., Gallagher, B., Roper, A. and Kurowska, K. (2001) *Evaluation of the dissemination of active support training and training trainers*.

Perry, J., Lowe, K., and Felce, D. (2000) *Characteristics of staffed community housing services for people with learning disabilities: A stratified random sample of statutory, voluntary and private sector provision*.

Lowe, K., Felce, D. and Blackman, D. (1996) *Challenging behaviour: the effectiveness of specialist support teams.*

Lowe, K. (1992) *Community based services: What consumers think.*

Lowe, K. and de Paiva, S. (1991) NIMROD :

Mansell, J., Beadle-Brown, J., Whelton, R., Beckett, C. and Hutchinson, A. (2008) *Effect of service structure and organisation on staff care practices in small community homes for people with intellectual disabilities.*

Beadle-Brown, J., Mansell, J. and Kozma, A. (2007) *Deinstitutionalization in intellectual disabilities.*

Adams, L., Beadle-Brown, J. and Mansell, J. (2006) *Individual planning: an exploration of the link between quality of plan and quality of life.*

Mansell, J. and Beadle-Brown, J. (2005) *Person-centred planning and person-centred action: A critical perspective.*

Mansell, J. and Beadle-Brown, J. (2004) *Person-centred planning or person-centred action? Policy and practice in intellectual disability services.*

Mansell, J. and Beadle-Brown, J. (2004) *Person-centred planning or person-centred action? A response to the commentaries.*

Mansell, J., Beadle-Brown, J. and Clegg, S. (2004) *The situation of large residential institutions in Europe.* In G. Freyhoff, C. Parker, M. Coué, & N. Greig (Eds.),

Jones, E, Perry, J, Lowe, K, Felce, D, Toogood, S., Dunstan, F., Allen, D, Pagler, J. (1999). *Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training in active support.*

Stancliffe, R. J., Harman, A. D, Toogood, S., McVilly, K. R. *Australian Implementation and Evaluation of Active Support.*

Further reading

Health

UK health and learning disability network

www.jan-net.co.uk

Department of Health

www.dh.gov.uk/heathersearch/?searchTerms=learning+disability+publications

Learning Disability Observatory

www.improvinghealthandlives.org.uk

PMLD Specific:

Raising our Sights

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

PMLD Network

www.pmldnetwork.org

PMLD Link

www.pmldlink.org.uk/

PMLD Factsheet

www.pmldnetwork.org/pmld%20definition%20factsheet%20-%20standardpdf

Mencap's PMLD Communication Guide

www.mencap.org.uk/page.asp?id=1539

Easy Read

Easy Health

www.easyhealth.org.uk

Change

www.changepeople.co.uk

Human Rights

www.improvinghealthandlives.org.uk

This report was produced by the **Association for Real Change (ARC)** for the Active Support Project: '**Creating An Ordinary Life**'. The project was funded by the Department of Health.

For more information about the project and ARC, please visit our website:
www.arcuk.org.uk

Association for Real Change

ARC House, Marsden Street, Chesterfield, Derbyshire S40 1JY

Tel: 01246 555043 Email: contact.us@arcuk.org.uk

