

ESSENTIAL LIFESTYLE PLANNING AND ACTIVE SUPPORT

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Abstract

The White Paper, Valuing People (DoH, 2001) proposes Person Centred Planning (PCP) as a way for service users to exercise more power and control and have more fulfilling lives. Active Support (AS) is another approach that can improve the quality of life of people with severe disabilities by enabling them to participate as fully as possible in daily activities at home and in the community. PCP and AS have been developed and researched in different ways and are described using almost different language. Although they may seem an unlikely partnership, some approaches to PCP and some of the components of AS are complementary rather than mutually exclusive. Plans should generate new ideas and goals, but these need to be implemented if they are to affect people's lives. PCP can generate ideas, AS can put them into action, used together they may provide a better way to enable service users to participate in ways that reflect what is important to them and significantly improve their quality of life. A case history illustrates this potential, and describes how a particular form of PCP 'Essential Lifestyle Planning' (ELP) was used in conjunction with some of the planning and programming components of AS by a staff team supporting a man called John who lives in Oxfordshire. An 'Essential Team Plan' was also developed to positively utilise staff interests and resources to maintain and improve outcomes for service users. The case history demonstrates that each approach has a contribution to make to the other and highlights the potential for further attempts to combine both approaches in conjunction with more rigorous research on evaluating the impact on the quality of life of service users in future studies.

Introduction

People with more severe disabilities have higher support needs and, therefore, by definition need high levels of contact and assistance from staff. However, in institutions they were unlikely to receive it and were often bored, lonely, and spent little time actively involved in anything interesting or worthwhile as a result (Grant and Moores, 1977; Pratt, Bumstead and Raynes, 1976; Dailey, Allen, Chinsky and Viet, 1974; Raynes, 1980).

This problem has not been solved simply by people moving to smaller scale community settings, but has been shown to be an enduring problem, even in well-resourced ordinary housing services, where staff have received values training and the organisational aims broadly conform to 'new paradigm' supported living philosophies (Felce and Perry, 1995; Emerson and Hatton 1994). Ensuring that service users are empowered and fully participate in all that a community has to offer has proved difficult for services to achieve. However, some services are attempting to resolve these problems by developing person centred planning systems (Sanderson and Gitsham in press). Whilst others are training staff to plan and interact helpfully with service users as part of a coherent structured approach which has become known as Active Support (Jones, et al., 1999, Jones et al 2001).

This article briefly describes Person Centred Planning (PCP) and Active Support (AS), and begins to explore how elements from each approach can be used together. This is illustrated by a case study integrating PCP and AS with John who lives in a group home in Oxfordshire. The outcome suggests that AS has a positive contribution to make to PCP especially regarding how plans are implemented, and PCP provides a good foundation for AS that may be better than other, more traditional, individual programme planning formats.

Person Centred Planning and Active Support

Central to the White Paper, Valuing People (DoH, 2001) is the process of PCP. Person centred planning involves continual listening and learning; focussed on what is important to someone with learning disabilities now and for the future and acting upon this in alliance with their family and friends. There are different approaches to PCP, for example, PATH, Essential Lifestyle Planning (ELP), Personal Futures Planning and Maps. All the approaches are based on the values of inclusion, and involve the following processes:

- Discovering what is important to the person (in their day to day life or the future), and what support they require
- Creating action plans so that the person has more of what is important to them in their life, with the support that they require
- Continuing to reflect and act on the actions and the plan

PCP is likely to be most effective where the same principles are applied to staff teams (Sanderson, 2000). This means that managers actively try to discover what is important to staff members and what support they require, and use this information when deciding on staff responsibilities and support systems (Sanderson, 2000). This is known as developing person centred teams, and the information about a team may be described in an 'Essential Team Plan' (Sanderson, 2000). PCP is one way that people in services can begin to address the problem of many people with high support needs being unfulfilled, lonely and bored.

AS provides another approach to resolving this problem. AS focuses on improving the quality of daily life experienced by severely disabled people. A central premise is that most typical members of society spend most of their time participating in various types of activities. We all make choices, but do not choose to do absolutely nothing for most of the time. Therefore, the amount of time a person spends participating in social, personal, household, leisure or other pursuits typical of daily living as opposed to having nothing to do, being passive or engaging in aimless or challenging behaviour are important ways of conceptualising and measuring quality of life (Felce and Emerson, 2000). People who have the most severe learning disabilities are often disengaged for most of the time (Emerson et al., 1999; Felce and Perry, 1995). So they need staff or other carers to give opportunity and provide the right level of assistance, if they are to participate in activities to a typical extent and thereby adopt valued social roles in line with O'Brien's (1987) five accomplishments (Felce, Jones and Lowe in press). However, even within their own homes many service users are prevented from participating and are excluded from daily life because they are viewed as incompetent. Research suggests that in reality, most people living in supported housing do not participate in constructive activities for more than a third of the time, and involvement can be virtually non-existent for more severely disabled people (Emerson and Hatton, 1994; Felce and Perry, 1995). This represents an unjust and unacceptable instance of life-wasting, which appears to be relatively widespread. In many contemporary services, although staff may be termed support workers, they are not trained to interact helpfully and most staff contact with service users has been shown to be in the form of conversation rather than assistance to participate in activities (Hewson and Walker, 1992; Felce and Perry, 1995). For example, Felce and Perry (1995) found that residents in 15 supported ordinary housing services in Wales, received contact from staff for an average of 15% of the time, and average levels of assistance were only 2.5%, which were clearly inadequate.

Active Support was developed in some of the original model ordinary housing services of the early 1980s (Felce 1989, Lowe and de Paiva 1991). The main components of Active Support include;

- a system for planning service users activities and staff deployment on a daily basis
- training for staff on how to interact with service users to assist them to participate in activity
- goal or ‘opportunity’ planning which expands the opportunities for participation in activities
- monitoring the level of service user participation in various activities on a daily basis.

The decision about what opportunities to pursue is done on the basis of the person’s existing individual programme plan, or is decided by staff with as much input from the person as possible.

The various components of AS have been empirically tested, and have been demonstrated to be effective by empirical research, over a considerable number of years (see for example Felce 1989, Repp, Barton, and Brulle, 1981, Porterfield et al, 1980; Mansell, Felce, de Kock, and Jenkins, 1982 Richman, Riordan, Reiss, Pyles, and Bailey, 1988). More recent experimental evaluations have shown that AS resulted in residents receiving significantly more assistance from staff and being significantly more engaged in activity (Jones et al. 1999; 2001)

AS has been criticised for being ‘old fashioned’ and not taking on board individual preferences and interests because it assumes that participation in any typical, constructive activity is good. PCP has been criticised for not sufficiently focussing on implementing planning, with the risk that the planning process does not lead to major changes in service user’s lives. PCP and AS have been developed and researched in different ways with the result that they tend to be described using almost different languages and seen as mutually exclusive ways of improving service quality. AS has been researched using direct observation and quantitative methods (Felce et al 1989, Jones et al 1999, 2001) where as most of the research into person centred planning has been qualitative (Holburn in press, Sanderson, 2000). Although they may seem an unlikely partnership, some approaches to PCP and some components of AS when used together may provide services with a better way to begin to support people to be engaged in ways that reflect what is important to them and therefore have more fulfilling lives.

Case History: using ELP and AS with John

Background

The following case history describes an attempt to use one approach to PCP called Essential Lifestyle Planning (ELP), and some of the planning components of AS with John. John is in his thirties and lives in a house in Oxfordshire with, Paul, Dave and Andrew. All four men have been described as having learning disabilities and challenging behaviour. They live in the same house because the staff team are skilled in supporting people who find it generally difficult to live successfully in the community. They did not chose to live together and sometimes John gets upset because things that he enjoys don’t happen or because he does not know what is going to happen during the day or which staff will be working with him. John has some physical problems and it is necessary for him to follow a programme of exercises each day. He needs help from staff to do these.

Twelve members of staff employed by Oxfordshire NHS trust work at the house; there are always three people on duty at any time during the day and one at night. There is a full time team leader responsible for managing the support of the people who live in the house and developing the staff team. The team leader had previously been involved in using AS in a different setting. She had found it to be very helpful in organising staff time, and improving staff accountability and the consistency of support provided. Oxfordshire Learning Disability NHS Trust is implementing ELP and staff have been exploring different ways of ensuring that the plans were implemented (Sanderson and Gitsham, in press). The team leader wanted to find better ways to plan and organise the team's work to ensure that all areas highlighted in someone's ELP actually happened.

One of the areas that the team leader had highlighted as a problem was that John's exercises did not always happen. Although this was discussed at each team meeting, it seemed that whatever the team agreed, there were still problems in getting staff to provide support for John to do exercises as often as they should. There were also issues about supporting John and his housemates to understand what was going to happen each day or week and who with. Like many of us, John wanted to know if the things that he liked would actually take place and who would be helping him. As a result he would ask constantly when he would be doing different things and become quite agitated if he did not receive a clear answer. This could trigger challenging behaviour, as he would sometimes feel let down because things that he wanted to do did not happen. The ability to predict what is likely to happen next is an important way of gaining control over situations, and John needed more help from the staff team to do this.

The problems were addressed by gathering detailed information about what was important to John, how he wanted to live his life and be supported, and having a structured way of making sure this happened. The team leader decided to try to combine ELP with AS to do this, in the following ways:

- ELP was used to discover what was important to John (including what activities he wanted to be involved in) and what support the staff needed to provide
- an Essential Team Plan (Sanderson, 2000; Sanderson and Smull, 2001) was developed to identify what was important to staff and what support they needed
- These were implemented using an 'Activity and Support' plan similar to one used in AS (Jones et al, 1999)
- A schedule of daily monitoring was developed, based on a recording component from AS (Jones et al, 1999)

Using essential lifestyle planning (ELP)

The team leader was trained to facilitate ELPs by attending a four-day training course. The rest of the team attended an awareness day in order that they understood the principles of this approach and could contribute to it. The staff team then gathered information to develop plans for John, Dave, Paul and Andrew, by talking to each person, the staff team and others who knew them (for a full description of the process see Smull and Sanderson, 2001). The ELP described what was important **to** John from his perspective (under the headings 'essentials' 'important' and 'enjoys/prefers'), and what was important **for** John to be healthy and safe, and to have what is important to him (under the heading 'to be successful in

supporting John we must...'). Once the ELPs were completed and checked, the team were ready to start developing an essential team plan.

Developing the Essential Team Plan (ETP)

The team leader organised a team day to develop the ETP, and then a further day for developing the implementation plan. The process for developing the ETP included exercises to help the team get to know each other's strengths, weaknesses, interests and preferences and identify any problematic issues that needed be resolved. The ETP stated how team members would work together and support each other and what the team leader expected of the team and what they expected from her.

Developing the implementation plan (using components from AS)

The second day included developing ideas about how the team could ensure that the essential lifestyle plans happened. The essential and important sections of their plan were summarised and the times they wanted them to happen highlighted, this was used to draw up an outline Activity and Support plan. However, programming only the essential and important things highlighted the empty times or gaps that remained in John's (and his housemates) daily life. These gaps were used as opportunities for John to participate, staff offered John things to do from the summarised lists identified in the 'enjoys' and other sections of the ELP.

The Activity and Support plans were completed weekly at the same time and each shift had a named person responsible for ensuring that all team members on duty were aware of what needed to happen. A straightforward monitoring sheet was also used to record the frequency of participation in activity. The staff team made lots of changes to this system in the early stages until it worked for them and the people they support. John now has a sheet with pictures of many of the activities on it so that John and others can see what and when things will happen, such as bowling.

The information about what staff members enjoy and were good at was used to match staff skills and interests with particular activities by putting staff member's initials by the activities to take place (e.g. one team member really did not enjoy swimming so other team members provided support for this activity). Further improvements were made by incorporating staff photos onto the sheets so that service users could see who would be supporting whom with what.

How well did it work?

The team reported that things improved considerably and John's exercises happened much more consistently and he participated in other, new activities as well. Developing ELPs has meant that the team have learnt a lot about the people they are supporting and what they want to do with their life. The Activity and Support plan helped with consistency, by clearly programming activities. Allocating a named person to support John (and other housemates) in specific activities has improved continuity and accountability. Staff were clearer about what they are doing at work and why, and last minute problems with things like drivers or vehicle availability avoided. Using pictures on the planning sheets made them more accessible and meant that John, Paul, Dave and Andrew could see for themselves what was going to happen and can have control over when some things take place. Everyone living in

the house now takes less medication, possibly because they are less anxious about what they will be doing and there were fewer incidents of challenging behaviour.

Taking into account staff strengths, preferences as well as those of people being supported appeared to assist with implementation. Spending time on their team plan has meant that staff learnt a lot about each other and there was a better matching of staff skills to service user need. This also seemed to improve the quality of interaction, staff reported that all activities are more enjoyable for service users because the staff enjoyed them too. Staff felt empowered as they have developed the system themselves and continue to adapt it overtime. The support workers take the lead on day to day arrangements and do not feel that they are being told what to do by their team leader.

Staff were initially resistant to the idea of recording and monitoring. They saw this as more work and possibly a management tool for checking on them. However, now the team manager uses the monitoring information to provide team members with positive performance feedback i.e. letting staff know when they are doing the right thing, which staff find useful and motivating. The ELPs are now more dynamic and change to reflect when someone has tried something new that they enjoyed. Commissioners and senior managers can see from the records that the ELPs are having a positive impact on the quality of service users lives.

Discussion

This case history, although obviously very limited in scope, illustrates the potential for ELP and AS to compliment one another and bring real benefits to people living in supported housing services. The two approaches are not mutually exclusive; an effective long-term planning system that actively involves the individual is a key requirement in the provision of a quality service. However, plans need to address major issues concerning service user's quality of life, in order to be effective.

There are different forms of PCP, and there is clearly the potential for variation in the content of what is described as 'Active Support' and in the format for staff training. Only elements of 'Active Support' as exemplified by the package of materials recently developed and tested by the Welsh Centre for Learning Disabilities Applied Research Unit (see Jones et al.1999; 2001) were adapted and use by the staff team in this case history. The most notable omission was the provision of staff training regarding helpful interaction both in theoretical terms and, more importantly, individual practical follow-up 'interactive' training sessions with each member of staff working with the service users in their own homes. The practical sessions are designed to assist staff in putting the theory into practice, and research on the impact of training staff in AS suggests that when this element is omitted then the training tends not to be effective (Jones et al, 2001).

The case history tends to confirm that without interactive training, the impact of planning can often be to increase the frequency of external activities that may be important to the person, but the risk remains that the person's level of engagement in these activities is unaffected. When interactive training is conducted in the person's home, then a wide range of opportunities to engage in domestic activities can also be easily accessed. These provide a useful and meaningful daily menu of valued activities which can be used in conjunction with

external, community based activities to provide variety and a more meaningful and fulfilling life. Research indicates that despite being amongst some of the most readily accessible activities available, staff in many supported housing services see domestic activities as being their exclusive responsibility (Bratt and Johnson 1988; Hewson and Walker, 1992; Felce and Perry, 1995). In this situation staff become a disabling barrier, denying service users access and relieving them of responsibility as though staying in a hotel. The result is that many service users are tenants in name only, since they are excluded from their own household and prevented from exercising control over a very important range of activities that most members of society regularly and frequently undertake. In contrast, when domestic activities are viewed as opportunities for service user participation and staff are trained to interact helpfully, then the service user takes on the role of competent householder and can exercise informed choice and control. Indeed, during the process of interactive training it could be argued that they effectively teach the support worker what the best ways of supporting them really are, facilitated by the trainer. The case history suggests that the fuller implementation of the Active Support package in its entirety would bring further improvements.

Without the focus provided by AS on service users daily activity and recording levels of participation, many services typically only systematically record negative or problematic behaviour and largely ignore positive or constructive behaviour. The case history confirmed that the use of participation records in a team meeting to provide performance feedback to staff was an important element in managing the team effectively and maintaining staff motivation. This highlights the need for training and other attempts to introduce new ways of working such as PCP and AS to be reinforced by ongoing management attention if they are to be successful. The adoption of a quality circle type approach to show staff how well they are doing, identify areas for improvement and developing the interactive approach over time, is a key recommendation within the AS package. The idea of developing Essential Team Plans that utilise the strengths, interests and support needs of the staff teams could be useful regarding the implementation and maintenance of AS. Team plans would be compatible with the quality circle type managerial approach, harnessing the creativity and initiative of team members and increasing their ownership of AS. This in turn could help in promoting the individualisation of the approach with service users.

Clearly in the case history presented, the manager had a good understanding of both AS and ELP and was already committed to both approaches. Her support to team members was probably the main factor in ensuring the success of the project. However, both AS and ELP need to be integrated into organisational culture and day to day management practice if they are to have a sustained impact. This requires management attention at more senior organisational levels (for a discussion of this in Oxfordshire Learning Disabilities NHS Trust see Sanderson and Gitsham, in press and in more general terms, Jones et al 2001).

ELPs and As are both concerned with achieving real change and empowering people with severe disabilities, they share a similar value base and there is scope for greater integration of both approaches.

The Potential Contribution of Active Support to Essential Lifestyle Planning

- Training and materials on essential lifestyle planning (Smull and Sanderson, 2001) include strategies for implementing the plans. Active Support offers another systematic

way of organising the implementation of planning, which has been demonstrated by research.

- Active Support reminds us of the importance of engagement in activity in general and the issues of participation in the home. An essential lifestyle plan records how someone is currently being supported. Active Support can be used to improve the quality of this support, through interactive training and describing in the essential lifestyle plan detailed information about the type of prompt and engagement techniques.

The Potential Contribution of Essential Lifestyle Planning to Active Support

- ELP offers a more detailed approach to discovering what is important to the person and the supports that they require than most forms of traditional Individual Programme Planning (often used as the basis of Active Support).
- The idea of developing 'person centred teams', and Essential Team Plans that describe utilise the strengths, interests and support needs of the staff teams can be useful in Active Support.

AS provides a tried and tested technology for staff to use to involve people in daily life. ELP offers a more detailed approach to discovering what is important to the person and the supports that they require than many forms of traditional Individual Programme Planning, currently undertaken by services. Active Support can then be used to improve the quality of support, through interactive training and helping the person to participate, so that they develop new skills and interests and become a valued active member of their own household and community. Put simply, essential lifestyle planning contributes the 'what is important to this person as an individual in their own right' and AS provides another way of organising the 'how we can make this happen'.

Conclusion

Further research and practice is needed to confirm whether integrating AS and PCP is effective in achieving positive change for people with high support needs on a larger scale. This could include using qualitative methods to understand staff and service users views about AS and more quantitative methods including direct observation to assess the impact of PCP. The case history indicates that AS and ELP have different functions and they can be used together to improve outcomes for service users. Any discussion about whether one is better than the other misses the point and wastes time. Services need to give up the search for a single solution to what remains a complex problem and aspire to achieve multiple competencies instead. A combination of PCP with AS may provide a more comprehensive means of improving service quality than either approach alone. If the vision of the White Paper is to be realised, services must explore how PCP can result in real change in people's lives and not simply superficial compliance with a new instruction. A combination of person centred planning with Active Support may hold some of the answers to ensuring that plans focus on what is important to someone, make a difference in their life, and positively utilise staff interests, capacities and resources.

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