

## **Active Support and “meaningful activity.”**

### **What is the meaning of “meaningful”?**

Active Support is an approach that aims to engage people in meaningful activities. It is one of the best evidenced models of support for adults with learning disabilities (Mansell and Beadle-Brown, 2012). Adults using challenging behaviour are more likely to be excluded from activities and the community, and when living in in-patient settings, more likely to live in impoverished environments, with a lack of occupation and meaningful activity and be avoided by staff (Department of Health, 2007; Mansell, 1995). Active Support is integral to Positive Behavioural Support (PBS) and the PBS competency framework (PBS Coalition UK, 2015) recommends building appropriate levels of participation in meaningful activity.

Subsequently, the prefix “Person-Centred” has been added to Active Support, to encourage an individualised approach to be used. Born out of deinstitutionalisation and an admirable desire for people with learning disabilities to have the chance to live an ordinary life, it was an understandable reaction to these people being denied freedoms, community access and any element of an ordinary life in the institutions. People in these settings were usually unengaged in any meaningful activity, rather, they were inactive or engaged in “meaningless” activities and unengaged with their support staff. This was especially the case for people with severe and profound learning disabilities. Originally based on the support provided at one of the first community-based homes (Mansell et al., 1983, 1987), Person-Centred Active Support has gathered momentum across the UK and is now widely used in supported living settings.

People both with and without learning disabilities like to be busy (Allen, et al., 2013). Busy people, meaningfully occupied, are likely to have a better quality of life, to be happier, and have less need to use challenging behaviour to get what they need and want (Jones et al., 2013). There is good evidence, in general, that a blend of personal care, productive and leisure activities are essential for well-being (Law et. al., 1998a; Townsend and Polatajko, 1997; Wilcock, 1998). Engagement in activities of daily living and social relationships are universally linked to quality of life (Power, Harper & Bullinger, 1999). Occupation is viewed as an essential human right within government documents for people with learning disabilities (Department of Health, 2001, 2009, 2010). Implicit in this is the one-to-one attention the person will be receiving, giving time for communication opportunities and positive social interactions.

Quality of life domains and measurement have been described in numerous models and an agreed framework was developed by the International Association for the Scientific Study of Intellectual Disabilities (IASSID) (Mansell & Beadle-Brown, 2012, p. 34- 35). The eight domains are: social inclusion, physical well-being, interpersonal relations, material well-being, emotional well-being, self-determination, personal development and rights. Active Support, in enabling an individual to engage in meaningful activities and the associated relationship development with the support staff that fosters, aims to make gains in most of these domains.

In the Active Support literature much is made of the importance of engagement in activities of daily living and the pursuit of the “ordinary life” (King’s Fund, 1980; Mansell & Beadle-Brown, 2012). The risk here is that the service user is then diverted from activities which are perceived as “meaningless” by the support staff, which nevertheless have vital meaning to the service user. There has been some criticism of the concept of normalisation and the tendency for diversity and individuality to be overlooked as a result (Brown and Smith, 1992). They may be engaged in the “meaningless” activity to cope with sensory input, to create order, or to feel in control. If the person has an impoverished history, it might be that this “meaningless” activity has filled a void due to a lack of opportunities in the past. Although it may have an unfortunate cause therefore, it may still have great importance for the individual.

Despite the centrality of Active Support to good quality person-centred care, more could be done to define what constitutes a meaningful activity. Is it supposed to be meaningful to us or meaningful to the person being supported? Given a choice between joining in with a person lining up their toy cars on their bedroom floor (meaningful to them) and supporting someone to make their bed (meaningful to us) what would a support worker choose to do and with what consequence? By its very nature Active Support, in increasing choice, will be diverting the person away from the activities or inactivity they have been occupied with in the past. Unless defined, in detail, with case studies where prioritising is complex, it could be down to individual staff opinions and biases as to what constitutes “meaningful.” It is hoped that careful assessment of the person and a proper functional analysis of their behaviours and activities will provide rigour to decision making on this issue.

The National Institute for Health and Care Excellence (NICE, 2013) define meaningful activities as “physical, social and leisure activities that are tailored to the person’s needs and preferences. Activity can range from activities of daily living

such as dressing, eating and washing, to leisure activities such as reading, gardening, arts and crafts, conversation and singing.” Egan and DeLaat stated, “meaningful activities are those which fulfil a goal or purpose that is personally or culturally important” (cited in Law, Polatajko, Baptiste, & Townsend, 1997, p. 36). Participation in such activities is seen as meeting psychological, biological and cultural needs; it also provides opportunities to discover new information, to create, promoting a sense of mastery and self-worth (Kielhofner, 1992). Other benefits described are quality of life, health in general and our very survival (Yerxa et al., 1990; Yerxa, 1998). Townsend and Brintnell (1997) noted that occupation promotes connection with others and contributes to the making of meaning for people.

Mansell & Beadle-Brown in Active Support (2012) explain: “[meaningful activity]...means activity that is likely to increase the person’s independence and control over his or her environment and to develop and sustain the relationship he or she has with other people.” In the PBS competencies framework (PBS Coalition UK, 2015) more useful detail is outlined. A person’s preferences, hopes, dreams and desires need to be identified, and a range of activities offered. Support should be given to enable the person to make informed choices between activities. In addition, we are to “help the person to do things they do not like, but that are essential.”

Mansell et al. (2002) suggest that one of the four components of Active Support is that “service users are offered opportunities to take part in everyday activities at home and in the community, rather than childish or special therapeutic activities.” Mansell et al. (2012) encourage the use of age appropriate activities and materials and yet also stress the importance of communicating at the appropriate developmental level of the person. Age appropriateness goes against person-centred support and provision of choices that have meaning for the person. Psychologists such as Piaget (1952) have shown that in order to optimise learning, the gap between what is known and what is to be learned cannot be too big or too small. Nind and Hewett (1996) go on to say, “in order to treat people with learning difficulties [sic] with respect, our behaviour in relation to them must surely have to take into account their level of language development, their understanding of the social world and their emotional maturity.” In other words, we need to meet the person where they are at, with proper regard to their developmental level as well as their chronological age.

Care is needed when using Active Support with people with autism who might engage in stereotypical repetitive behaviours. Should we set limits on how long they self-occupy for before we encourage them to do the housework? How much time and effort should be spent bringing them into “our world” through encouragement, prompting and directing and how much time should we attempt, with sensitivity, to be invited into “their world” through signalling our interest, availability and respect for what they are already doing? (Ashman et al., 2010). In terms of relationship building, the latter may provide a more solid foundation. Stereotypes are even defined as behaviours of concern in some of the literature (Ockenden et al., 2013). Williams (1996) writing as an autistic person herself, states that “behaviour modification generally allows for little ownership over one’s own behaviour, except where it adheres to what is desired by the professional or carer and their definition of ‘normal’, non-‘autistic’ behaviour.” Diversion away from stereotypes may actually be teaching people compliance. Where those stereotypes are established due to sensory processing needs, encouraging the person away from them may be extremely distressing. Milton (2014) points out that the behaviours of the person with autism are often being labelled as positive or negative (meaningful or meaningless) by a non-autistic person without any regard to the subjective, lived experience of the person.

Conversely, staff may think the person sat watching TV all day is engaged in an activity that has meaning for them. However, that “meaning” for them may be that it is safe, familiar and predictable and protects them from unknown and unfamiliar events and situations. Meaning can take time to find, through repeated exposure and experience and the engagement with another person alongside the activity. As well as helping the person to learn how to make choices (Mansell & Beadle-Brown, 2012), service providers need to learn how best to offer choices so that challenges are available within a safety-net of familiarity.

Attending to a person’s hopes, dreams and desires and supporting informed choices will be a challenge when working with a person with more complex needs. People who cannot easily express choice are more at risk of being given restricted or even meaningless opportunities. Ashman et al. (2010) outline useful procedures for developing connections with people, notably with the use of the SPELL framework and Intensive Interaction. In being enjoyable, undemanding and responsive, Intensive Interaction can build rapport and relationships, on the person’s terms. This is a desirable outcome in itself, but it can also be a stepping-stone to moving forward together into choice making and sharing meaningful activities.

As with everything, it is a question of balance and discussion. Good quality training in Person-Centred Active Support and good supervision and practice leadership are required to ensure the best, most individualised application of the concept of meaningful activities. Periodic Service Reviews should not look at levels of engagement in activities, for that is meaningless, rather, at indicators of quality of life as a result of engagement and associated relationship development.

Despite no declaration of conflicts of interest, much of the research on the effectiveness of Active Support has been conducted by those who designed, developed and disseminated it. The research does indeed show an increase in engagement with activities. However, there is a lack of evidence that this has improved peoples' quality of life. With stereotypies sometimes defined as behaviours of concern, and when increased occupation (facilitated by diversion away from stereotypies) has occurred, by definition behaviours of concern will reduce – even if the person is more distressed as a result. A notable gap in the research is around which activities lead to quality of life improvements. Research in this area is complex as Active Support, especially within PBS, is usually part of a multi-component intervention with many variables.

In their systematic review, Hamlin and Sturmey (2011) conclude that Active Support is a “promising treatment” not an “evidence-based practice,” as defined by Chambless and Hollon (1998). Ball and Fazil (2012) found that engagement in “low-demand sensory activities” was more effective in reducing challenging behaviour than other types of engagement. Bradshaw et al. (2004) were the only research group to use a control group in order to compare the changes. They found that Active Support actually increased challenging behaviour. The authors suggest that this could be the result of an initial increase in demand but hypothesised that with time, service users may develop tolerance to demands and in the long-term, this could reduce challenging behaviours.

It is helpful here to think of ourselves and the activities we do that have meaning for us. We can make unwise choices, we can choose to do nothing, we can choose not to do any housework for a week or two or we may pay for someone to do those activities that we “do not like but that are essential.” The College of Occupational Therapists (COT, 2005) argue that occupational therapists are best placed to provide support to plan and implement meaningful occupation. Wilcock and Hocking (2015)'s model of the four types of occupation ('being', 'doing', 'belonging' and 'becoming') may be helpful to identify a balanced range of activities. Goldberg et al. (2002) conclude that for best life quality outcomes, clients must define what is meaningful for them and that activities that give a sense of control and just the right amount of challenge are to be encouraged. In reviewing a recent book on belonging for people with profound learning disabilities, Hatton (2020) remarks, “many of the chapters in the book demonstrate the fundamental value of spending time hanging out with people, enjoying each other's company and being rather than necessarily doing something "useful." Individualised notions of competence and independence are shown to be radically irrelevant and harmful, where interdependence and distributed competence are what matters.”

To be, to engage with, to develop and sustain relationships, requires staff to be undemanding, attuned and responsive. Intensive Interaction provides a framework for being with, for focussing on mutual enjoyment and interdependence and allows support staff to value what has meaning for the person be it unusual or repetitive. Being with a person and responding to *their* activities will engender feelings of control, agency and self-esteem. Maximising quality of life outcomes requires these complex issues to be carefully considered, planned and implemented within a robust and meaningful system of practice leadership and Periodic Service Reviews.

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