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Challenging behaviours in adults with an intellectual disability, and the active support model

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Challenging Behaviours in Adults with an Intellectual Disability, and the Active Support Model

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Summary

The present thesis focuses on challenging behaviours exhibited by people with an intellectual disability and the effects of Active Support, a potential environmental intervention, on the challenging behaviour and quality of life for people with an intellectual disability (ID). Challenging behaviours are frequent among people with ID and, in the absence of effective intervention, highly persistent. Findings from an 11-year longitudinal investigation of challenging behaviours in 58 adults with ID highlighted the chronicity of serious challenging behaviours (Chapter 2). Participants who exhibited severe physical attacks, self-injurious or stereotyped behaviours were more likely (by about 200%) to still exhibit these behaviours at severe levels 11 years later. An environmental broad antecedent intervention (Active Support) is proposed as one alternative approach to individualised behavioural interventions, which are rarely available in services for people with ID and challenging behaviours. Active Support is a multi-component person-focused model which aims to improve the quality of life of people with ID living in residential settings, by putting in place a system that ensures opportunities for daily participation in meaningful activities and receipt of staff support. The evidence pertaining to the effectiveness of the model in improving the quality of life for people with ID was reviewed and a theoretical description of the model's potential to act as a proactive intervention for challenging behaviours was put forward (Chapter 3).

Evaluation of Interactive Training for Active Support, the training component hypothesised to produce more immediate effects on residents' challenging behaviours, showed no overall group-level increase in activity participation or any decrease in challenging behaviours for 21 adults with ID, while observational evidence suggested that quality of staff support improved immediately after Interactive Training (Chapter 4). Despite the absence of a group-level change in resident behaviours, there was some evidence that Interactive Training had an immediate effect on the engagement levels of individuals with more frequent aggressive and destructive behaviours. In the final study reported in this thesis (Chapter 5), 37 staff in ID services who had received Interactive Training were interviewed about their training experience, and, also, their views on the Active Support model which they had been using for a period of about two years. While the majority of staff viewed Interactive Training as a positive experience which had an impact on the way they worked, they suggested that successful implementation of the whole Active Support model is complicated by residents' challenging behaviours and lack of managerial support. The Active Support model may be most effective when both training components- workshops and Interactive Training- are offered to staff in community services. Our understanding of the effects of Active Support on challenging behaviour would benefit from further research which focuses more specifically on people with ID and challenging behaviours.

Chapter 1: Introduction

The focus of the present thesis is on the challenging behaviours of people with an intellectual disability (ID). Challenging behaviours persist throughout life and are a major ongoing challenge in services for people with an ID. In the present Chapter, I describe how the remaining chapters in the thesis contribute to our understanding of challenging behaviour and a broad-based environmental intervention (Active Support) that may provide a context for the effective remediation of challenging behaviours.

Challenging Behaviours and Intellectual Disability

The term 'challenging behaviour' has been used to describe a wide range of "culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities" (Emerson, 1995, pp. 4-5). Challenging behaviours may include aggressive, self-injurious, destructive, socially inappropriate, or stereotyped behaviours, the impact of which places a significant risk on the well-being of the person who exhibits them and/or those who live in his or her proximity. Despite the heterogeneity of the behaviours encompassed in this term, it was originally adopted to emphasise the challenges that these behaviours place upon the immediate environment, rather than the persons who exhibit them (Blunden & Allen, 1987). In this context, Toogood (1993) suggests that, while the main dimension of this socially constructed term is its negative impact on a person's quality of life, another important dimension relates to the restricted capacity of service systems to provide the range of supports required to attain a normal lifestyle. However, over time the term challenging behaviour has increasingly been used as a diagnostic label – as a property of an individual with ID – rather than a dynamic social construct. For this reason, a revised

definition has been recently proposed by a joint working group of the Royal College of Psychiatrists, British Psychological Society, and the Royal College of Speech and Language Therapists to re-emphasise the dynamic nature of these behaviours:

> "Behaviour [...] of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses from individuals or services that are restrictive, aversive or result in exclusion."
>
> (Banks et al., 2007, p.14).

Challenging behaviours have detrimental effects on the quality of life of people with ID (Felce, Lowe, Beecham, & Hallam, 2000; Felce & Perry, 2004), the psychological well-being of their family caregivers (Hastings, 2002a, 2003; Hastings, Daley, Burns, & Beck, 2004, Hastings et al., 2005; Plant & Sanders, 2007; White & Hastings, 2004), and the well-being of care staff (Hastings, 2002b, 2005; Hastings & Brown, 2002). Challenging behaviours are also associated with increased service costs (Knapp, Comas-Herrera, Astin, Beecham, & Pendaries, 2005), which are disproportionately higher than those associated with caring for people without challenging behaviours (Allen, Lowe, Moore, & Brophy, 2007). Challenging behaviours affect a considerable number of people with ID (10-15%; Emerson et al., 2001a; Holden & Gitlesen, 2006; Lowe et al., 2007; Qureshi & Alborz, 1992).

Data from studies on challenging behaviours indicate long-term persistence of challenging behaviours (Emerson et al., 2001b; Murphy et al, 2005), although relatively little is known about the factors that facilitate maintenance of these behaviours over long periods of time. In this context, a longitudinal investigation of challenging behaviour is presented in Chapter 2. Challenging behaviours were measured in a group of 58 adults over a period of 11 years and persistence was explored using three complementary statistical indices. To investigate whether people with persistent

challenging behaviours were systematically different from other groups of people with ID, we compared the personal characteristics of people with persisting challenging behaviours and those who never exhibited severe challenging behaviours. The differences in the personal characteristics of these two groups were not systematic enough to indicate that certain personal characteristics were associated with long-term maintenance of challenging behaviours. It is very likely that maintenance of challenging behaviours is facilitated by other environmental factors, such as the behaviour of carers. Physical attacks, stereotyped and self-injurious behaviours were highly persistent over an 11-year period, indicating that, in the absence of effective interventions, these difficult behaviours are unlikely to be removed from the behavioural repertoires of adults with ID. Findings from this longitudinal study highlight the need to develop intervention programmes which can effectively reduce severe challenging behaviours and prevent their long-term maintenance. The remaining chapters in this thesis explore how Active Support, a model for organising the daily life of people with ID, can act as preventative intervention for challenging behaviours.

Interventions for Challenging Behaviours

Given that challenging behaviours affect a significant proportion of people with ID and that these behaviours have considerable negative consequences for the people who engage in them and their carers, it is important to ask what can be done to ameliorate these effects. Evidence from meta-analyses of single-case studies suggests that interventions for challenging behaviours based on behaviour analytic approaches are effective (Campbell, 2003; Didden, Ducker, & Korzilius, 1997; Didden, Korzilius, van Oorsouw, & Sturmey, 2006; Scotti , Evans, Meyer, & Walker, 1991) whereas evidence for other interventions including psychopharmacology is much less well established (Ahmed et al., 2000; Didden et al., 1997; Singh, Matson, Cooper, Dixon, &

Sturmey, 2005; Scotti et al., 1991). In the behaviour analytic field, interventions for challenging behaviour based on an analysis of the maintaining consequences of behaviour have been extensively used. For example, once the maintaining consequences are identified, then communicative behaviours can be taught to produce these consequences (Functional Communication Training; Carr & Durand, 1985; Durand & Carr, 1991). In this way, a person is able to access the desired consequences though socially acceptable behaviours and does not have to resort to challenging behaviours, which are eliminated over time.

Researchers are also becoming increasingly more aware of the role of antecedent-based interventions for challenging behaviours (e.g., Carr, Reeve, & Magito-McLaughlin, 1996; Smith & Iwata, 1997). One category of antecedent events is known as establishing (Michael, 1993) or motivating operations (Laraway, Snycerski, Michael, & Poling, 2003). In the presence of these antecedent events, the motivation to exhibit a particular behaviour is altered; motivating operations change momentarily the effectiveness of the reinforcing consequences and the frequency of the behaviour that has been reinforced in this way in the past (Michael, 1993, 2007). In this sense, motivating operations are useful in enhancing our understanding of challenging behaviour, both in terms of why the behaviour takes place at a particular time and how its consequences are reinforcing it (McGill, 1999). Antecedent interventions focusing on changing motivating operations can be used to address challenging behaviours and have been associated with increased effectiveness in reducing or eliminating challenging behaviours (Didden et al., 2006). For example, in an environment where reinforcers (e.g., attention) are provided frequently and independently of the occurrence of challenging or adaptive behaviours, challenging behaviours that had been maintained by this reinforcer decrease (the motivating operation introduced in the environment is

called noncontingent reinforcement; Vollmer & Iwata, 1991; Vollmer, Iwata, Zarcone, Smith & Mazaleski, 1993).

Positive Behaviour Support (PBS), an approach developed to help people engage in appropriate behaviours and overcome challenging behaviours (Koegel, Koegel, & Dunlap, 1996) provides the framework for delivery of interventions whose effectiveness has been established through systematic research. The main goal of PBS is to improve the quality of life of the person with ID and all other relevant stakeholders, while a secondary goal is to make challenging behaviour 'irrelevant, inefficient, and ineffective' (Carr et al., 2002, p. 5). These goals are achieved by identifying the outcomes which are important to each person (e.g., through Person-Centred Planning) and using multi-component behavioural interventions which include modification of consequent and antecedent events along with skill and competency teaching (Dunlap et al., 2000).

Policy guidelines and professional ethics emphasise that evidence-based effective interventions should be made available to people with challenging behaviour (Ball, Bush, & Emerson, 2004; Van Houten et al., 1988). In practice, however, behavioural interventions such as those described briefly above are not widely available to those who need them. Studies of treatment practices in service settings report a small percentage of people with challenging behaviour as having a behavioural written plan (Emerson et al., 2000; Kiernan & Qureshi, 1993), even within specialist services for people with challenging behaviours (Robertson et al., 2005). In a large number of cases, people do not have behavioural support plans or access to psychologists, even when their challenging behaviour is the reason for moving into out-of-area placements (Allen et al., 2007). Informal interventions are more prevalent than formal written plans, even when such informal interventions are rather intrusive (Feldman, Atkinson, Foti-Gervais, &

Condillac, 2004). Even though descriptive studies of service practices do not include information on the quality of written behavioural plans when these are in place (Lowe, Allen, Brophy & Moore, 2005), they are important in highlighting the substantial number of people who are probably not in receipt of individualised, evidence-based behavioural programmes.

Active Support and Challenging Behaviour

Given the lack of availability of evidence-based interventions for challenging behaviours, research is needed to systematically explore the reasons behind the unavailability of individualised effective interventions and, probably simultaneously, develop alternative types of interventions which service systems may be more likely to adopt. In the present thesis, I focus on an intervention approach (Active Support) that may address this second point. Active Support has the potential to target more people by altering the general environmental context where challenging behaviours occur. In other words, a successful intervention may not need to target specific behaviours only; it could also target the environment which is challenged in the presence of these behaviours (i.e., address the antecedent conditions for challenging behaviours).

In Chapter 3, we propose that broad changes in the living and social environment of people with ID and challenging behaviour achieved through Active Support could have an indirect effect on their challenging behaviour through changes in the motivating operations for these behaviours. Active Support is a multi-dimensional model of care for community group-home residents that aims to increase the opportunities for participation in age-appropriate, meaningful activities with the appropriate support from staff (Felce, Jones, & Lowe, 2002; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002). In Chapter 3, we describe the Active Support model and its components, the relationship of Active Support to Normalisation theory, Applied Behaviour Analysis and other similar

approaches (Person-Centred Planning and Positive Behaviour Support), and review the available evidence on the effectiveness of Active Support in improving the quality of life for people with an ID.

Although Active Support is a model developed primarily to address quality of life issues through active participation in daily activities, we include a proposition at a theoretical level of how Active Support could act as a preventative intervention for challenging behaviours. Changes brought about in the social environment (staff behaviours and activity availability) may affect the likelihood of exhibiting challenging behaviours by affecting the motivation to engage in these behaviours. If Active Support has the potential to prevent challenging behaviours, its application in service settings might be an effective and less resource-intensive intervention for reduction of challenging behaviours.

Interactive Training for Active Support: Effects on Activity Participation and Challenging Behaviours

The Active Support model is implemented through group workshops and one-to-one Interactive Training offered to staff of community homes (see Chapter 3). Group workshops aim to introduce staff to the structural components of the model and familiarise them with their use. Interactive Training aims to help staff develop a range of behaviours which facilitate resident engagement in constructive activities on a moment-to-moment basis. Interactive Training involves one member of staff at a time and focuses on the way this staff member interacts with each house resident, in terms of amount, quality and effectiveness of support provided (Toogood, in press). Changes in the living environment would be expected to happen after the introduction of the structural components (group workshops), but changes in the social environment –interactions with staff– are expected to happen after Interactive Training.

While several studies have demonstrated the effect of the combined Active Support training methods in improving resident activity participation and staff support (Bradshaw et al., 2004; Felce et al., 2000; Jones et al., 1999; Mansell et al., 2002; Smith, Felce, Jones, & Lowe, 2002; Stancliffe, Harman, Toogood, & McVilly, 2007 – see full review in Chapter 3), the effects on challenging behaviours are less clear. We hypothesise that, if the Active Support model can affect challenging behaviours, it would be mainly through Interactive Training, which produces immediate changes in the amount and quality of staff support behaviours (Toogood, in press). The importance of changing staff behaviour both for the reduction of inappropriate behaviours and the increase of appropriate behaviours is highlighted by studies which indicate that staff responses to challenging behaviours may be reinforcing them and, thus, contributing to their long-term maintenance (Hastings, 1996; Hastings & Remington, 1994a; Watts, Reeds & Hastings, 1997).

The effectiveness of Interactive Training for Active Support in increasing resident engagement in activities, improving staff support and decreasing challenging behaviours for 21 adults with ID is examined in Chapter 4. Levels of resident activity participation, challenging behaviours and staff support were measured before and immediately after Interactive Training, and at six months follow up. Group-level findings indicated a lack of change in all resident behaviours (engagement and challenging behaviours). A significant increase in quality of staff support was evident immediately after the training, while six months later staff nonverbal assistance increased. This quantitative increase in staff behaviours was not supported by a qualitative improvement in eliciting engagement. The small number of participants who exhibited challenging behaviours in the presence of staff assistance behaviours prohibited the calculation of reliable indices of effectiveness of staff behaviours in

preventing challenging behaviours. However, sub-group analyses suggested that larger improvements in activity participation were evident in those residents who were perceived by staff as exhibiting significantly more frequent and severe aggressive and destructive behaviours.

Data presented in Chapter 4 suggest that Interactive Training alone, or divorced in time from workshop training, may not be effective in improving quality of life for people with ID. There was some evidence that people with challenging behaviours may benefit in the short term from Interactive Training for support staff, but these effects were not maintained. To explore potential reasons for these findings, 37 staff who participated in Interactive Training for Active Support were interviewed regarding their experience of participating in the training and, also, their experience of trying to implement the Active Support model over a period of about two years (Chapter 5). Findings suggested that Interactive Training was viewed by the majority of staff as a positive experience which helped them learn new skills about providing support. Partly consistent with direct observations of staff behaviour (Chapter 4), an increase in support skills was reported by most staff, with improvements in activity preparation and presentation being the most frequently reported. However, staff suggested that full implementation of the Active Support model is hindered mainly by lack of appropriate management support and by the additional complications caused by residents' challenging behaviours.

Discussion and Conclusions

Chapter 6 draws together the findings from all the preceding chapters and discusses how they enhance our understanding of challenging behaviours in adults with ID and the way environmental interventions could affect them. The methodological problems and the limitations on the interpretation of the findings are addressed, along

with possible directions for future research. Finally, implications for services that might adopt this model are drawn from the study findings. These relate mainly to the training format, and factors that may affect training and programme implementation.

Background to the Studies Presented in this Thesis

The present thesis was funded by the ESRC and North East Wales (NEW) NHS Trust through an ESRC CASE Collaborative Studentship. The academic partner was the School of Psychology, Bangor University, and the non-academic one was the Behavioural Support Team of NEW NHS. My role was to conduct the PhD research registered as a PhD student in the School of Psychology and as an Honorary Research Assistant in the Behavioural Support Team.

Shortly after the beginning of the studentship in September 2004, a research opportunity arose in NEW NHS: the Behavioural Support Team was invited to provide Interactive Training for Active Support to the staff of Community Residential Service as part of the Trust's service development programme. The staff of Community Residential Service had already received Active Support workshop training during the previous year. Following the workshops, Active Support training ceased. In December 2004, it was decided to complete Active Support training with the provision of Interactive Training. From the perspective of evaluation designs, this was not the ideal setting to conduct research in the context of the PhD goals. However, the Trust was very keen to have this piece of work evaluated, so I decided to take advantage of this opportunity, and treat it as an initial small-scale study which would lead into a larger-scale evaluation. In terms of the design of this evaluation, two options were considered: whether it would be a series of single case-studies or a group design. Given the small number of residents in the Community Residential Service, and the lack of research precedent in evaluating Interactive Training effects, I decided -in communication with

my supervisors- to adopt a group design which would maximise the power of subsequent analyses. At the same time, it was decided to have a control group. I met with Trust managers and proposed a control-group design where staff from half of the houses would be offered the training first, and the remaining would form a waiting list control group. However, the Trust was not interested in having a control group and decided that it would not be feasible to provide me with one, as they were planning to provide Interactive Training to staff in all12 houses in a very short period (three weeks).

Therefore, realistic restrictions led to the design of the study presented in Chapter 4. I began working on the research proposal and Ethics approval application for the Local Research Ethics Committee (LREC), which lasted longer than initially expected, as the LREC application form had just been extended. Approval for this study was requested and obtained by LREC, Research and Development Department of NEW NHS and the School's Ethics Committee. Although the whole procedure progressed very smoothly, it did take longer than expected and, finally, came to an end in June 2005. I then began the procedure of obtaining consent from potential study participants (Appendix 6) which was a multi-step procedure that aimed to ensure everyone's best interests. It was soon established that the majority of potential participants could not provide independent consent, so their relatives/representatives had to be contacted. This delayed substantially the whole procedure, which started at the end of June 2005, and was completed mid-October (when the last consent form was returned). In the meantime, the Trust postponed the Interactive Training for two reasons: to provide me with adequate time to conduct the baseline observations, and because August was imminent, a month when many staff take their annual leave and are unavailable for training. To compensate for the prolonged consent procedure, I adapted slightly the study plan, and commenced the baseline observations with participants whose consent

had been obtained, while awaiting consents from other potential participants. In September 2005, the Behavioural Support Team began Interactive Training. Instead of their initial plans of three weeks (plus one week for contingency), Interactive Training lasted five months, from September 2005 until January 2006. Obviously, this delay in training resulted in a delay of the post-training and follow up observations. The whole study was completed in August 2006, approximately half a year later than originally proposed.

My contribution to the above study consisted of: designing it; liaising with the NHS; writing the research proposal, the LREC, R&D and Ethics Committee applications; developing all documentation for consent procedure; liaising with the study participants and their representatives for obtaining consent; training myself and one other observer in the use of hand-held computers for real-time observations; training myself in the completion of the relevant rating scales; conducting 20 out of 23 baseline observations, 21 out of 22 post-training observations and 20 out of 21 post training observations; managing the data; analysing and writing up the study. In addition, I presented interim findings to NHS managers and wrote the end of study reports for the LREC Committee and the Research and Development Department of NEW NHS who had authorised the study. At the end of the study, I disseminated the findings to the two NHS departments who hosted this study, the staff and residents of the community homes, and the legal representatives of research participants.

Parallel to the study in Chapter 4, I conducted the literature review of the Active Support model, which is presented in Chapter 3 of this thesis. There were no complications with the timing of this study, as it was finished according to the initial plan in June 2006.

The next study to be conducted was the study presented in Chapter 5. The planning for this study started at the time of the post-training observations of the Chapter 4 study. During the post-training observations, my anecdotal conclusion was that Interactive Training did not have an obvious effect in the daily lives of the residents (as was later confirmed by the analyses in Chapter 4), so it was decided in communication with my supervisors to conduct interviews with staff who participated in the training. This study began in March 2006 and was completed in August 2006.

My contribution in this study was to design the interview protocol; to liaise with the Behavioural Support Team for organising the study; to apply for permission to conduct the study to the Research and Development Department of NEW NHS, registering it as an audit for the Behavioural Support Team; to contact all trained staff; to conduct all the interviews; to analyse the results; to train a second rater in content analysis; to analyse interrater reliability; and to write up the paper. At the end of the study, I wrote an end of study report to the Research and Development Department, the two NHS departments hosting the study, and a study lay summary for the staff who participated. I also presented the study findings in a managers' meeting of the Community Residential Service. Finally, the study was presented in two research conferences (US and UK based), and one conference for clinical practitioners (UK based).

The final study was the secondary data analysis presented in Chapter 1. Planning for this study started shortly after the post-training observations in Chapter 4. During this period, I presented the Chapter 4 interim findings to all managers of the Community Residential Service. The results indicated a lack of substantial change in the behaviour of staff and house residents. This finding in combination with organisational changes happening in the service at that time (management changes) resulted in the Trust

reconsidering its training priorities, and deciding that Active Support was not among them.

While unaware of the above developments, I had been designing a third applied evaluation of Active Support, which would include a series of case studies, where full Active Support training would be offered to staff, and a design of multiple baseline would be employed. In communication with my supervisor from the Trust, it became obvious that it would not be possible to conduct such as study within the NEW NHS, as no further Active Support training would be pursued. I started exploring other options available locally. Among the most promising ones were the North West Wales NHS Trust and the Bangor Centre for Developmental Disabilities. Eventually, they were both rejected for various reasons. One other ESCR student was already collaborating with North West Wales Learning Disability Departments. My presence would add additional burden to this service. At the Bangor Centre most of the staff were fully trained on Active Support, so I would need to wait for new staff to be recruited. Moreover, the future of the University's collaboration with the Centre was uncertain. Shortly after, ownership of the Bangor Centre was moved from the University to a private provider. In addition to all these complications, there were only 12 months remaining before completion of the PhD was expected. During those 12 months, I needed to analyse and write up the studies in Chapters 4 and 5, conduct a new study and write up the thesis.

Taking all the above factors into account, and in association with my supervisors it was decided to conduct a secondary data analysis. I had an option between two available datasets. The first one was an evaluation of Active Support in South Wales that was offered by Prof. David Felce (University of Cardiff). This dataset had been extensively analysed in the past (Felce et al., 2000; Jones et al., 1999; Jones et al., 2001a,b; Smith et al., 2002), but in discussion with Prof. Felce and my supervisors, it

seemed that the type of data collected could be used to answer the research questions of my thesis, and these data had not been used before (in specific, these data were the observation files for separate topographies of challenging behaviours.). After initial exploration of the data, and meetings with people who had contributed to the data collection, it was clear that the data was not suitable analysis. There were two main reasons for this: a. the low frequencies of observed topographies of challenging behaviours had not allowed the estimation of interrater reliability; and b. there were no reliable records of the equivalence between key presses during data collection and definition of variable measured. For example, it was unclear whether the key press for stereotypy was (,) or (/). Given that both symbols seemed to appear in the observation files, codes could not be estimated by a process of logical elimination either.

The second available database involved the collection of longitudinal data on the challenging behaviours of adults with an intellectual disability. These adults came from the same geographical area (North East Wales) as the adults who participated in the remaining studies. One of the advantages of this study was that it had not been analysed before. With the exception of a MSc thesis that was conducted on some parts of two separate databases, the longitudinal database was created by me. I received two Excel files with data from 1992 and 2003 separately, which I transferred to SPSS, cleaned and merged them into a longitudinal database. The other advantage of the present database was its relevance to the PhD focus. Although not a direct evaluation of Active Support, it provided an empirical rationale for the context of the remaining studies. With the main focus of this PhD being the potential of Active Support, and Interactive Training in particular, to act as preventative intervention for challenging behaviours, the study presented in Chapter 2 underlines the importance of intervening to reduce challenging behaviours. Chapter 2 emphasises the high persistence levels of severe challenging

behaviours over long periods of time, and thus highlights the need to develop effective intervention programmes.

My contribution to this study was the creation of the longitudinal database, the creation of separate databases for data collected for interrater reliability purposes, all the statistical modelling, and writing up of the paper. The results of this study were presented in two U.K. based research conferences.

Chapter 2: Persistence of Challenging Behaviours in Adults with Intellectual Disability over a Period of 11 Years.

Abstract

Challenging behaviours in people with an intellectual disability (ID) often develop early and tend to persist throughout life. This study presents data on the chronicity of challenging behaviours in adults with ID over a period of 11 years, and explores the characteristics of people with persistent serious behaviour problems. Support staff provided data on 58 adults living in a residential facility using an interview survey schedule assessing challenging behaviours in 1992 and 2003. Participants presenting with serious physical attacks, self-injury and frequent stereotypy were more likely to persist in these behaviours over time. The relative risk for severe self-injury in 2003 for those self-injuring in 1992 was 2.88. The relative risk over this period for physical attacks was 3.21 and for stereotypy 3.49. Individuals with persisting behaviour problems differed from those who did not present serious behaviour problems on the basis of their younger age, increased mobility, and decreased sociability and daily living skills in 1992. The relatively high persistence of serious challenging behaviours highlights the need to identify the factors related to maintenance of these behaviours over time. The participant characteristics and adaptive behaviours identified in the present study were not consistently related to the persistence of challenging behaviours. Therefore, other factors, including environmental characteristics, are likely to be related to challenging behaviour persistence.

Introduction

Challenging behaviours (such as self-injurious, aggressive, destructive behaviours) are frequent among people with an intellectual disability (ID). In general, prevalence rates have been reported at about 10%-15% (Emerson et al., 2001a; Holden & Gitlesen 2006; Lowe et al., 2007; Qureshi & Alborz, 1992). Challenging behaviours tend to be chronic with longitudinal studies measuring persistence percentages from 50% to 90% of people engaging in such behaviours at one time point still engaging in the behaviour several years later. Overall challenging behaviours have been shown to persist in 63% to 90% of people (Chadwick, Kusel, Cuddy, & Taylor, 2004; Kiernan & Alborz, 1996; Kiernan et al., 1997), even in children younger than four years (Green et al., 2005).

Considering individual topographies of challenging behaviour, stereotypy persisted in 62.5% of children (Chadwick et al., 2004), and was still measurable in adults over a period of 10 years (Jones, 1999). In one of the longest longitudinal follow-ups of people with an ID, stereotypy was displayed by more than 60% of the sample at baseline and 26 years later (Thompson & Reid, 2002). Severe self-injurious behaviours were persistent in 57% of adults over seven years (Emerson et al., 2001b) and in 75% of younger adults over five years (Kiernan & Alborz, 1996). Higher persistence rates are found for physical attacks, with Kiernan and Alborz (1996) reporting 83% persistence in a five year follow up, while Nøttestad and Linaker (2002) measured an eight-year persistence of physical attacks at approximately 87% (value extracted from published data). Persistence of destructive behaviour has been measured at levels of 70% and above (Emerson, Robertson, Folwer, Letchford, & Jones, 1996; Kiernan & Alborz, 1996).

In addition to measuring the percentage of people who persist with severe problems over time, chronicity of challenging behaviour has also been explored with measures of association. Studies measuring the relationship between earlier and later challenging behaviours have reported medium to strong correlations (e.g., .59 over five years, Kiernan & Alborz, 1996; .40 over 12 years, Murphy et al., 2005; .86 over about 4 years, Turner & Sloper, 1996). All of this information indicates that challenging behaviour is not a transient phenomenon, but persistent over very long periods of time.

Although the persistence of challenging behaviours is well established, our knowledge of the characteristics of people with persisting challenging behaviours is less clear. One reason for this is the paucity of studies that follow up people with challenging behaviours (McClintock, Hall, & Oliver, 2003). A second reason is that, among longitudinal studies, the focus is not always on correlates of persistence, but on concurrent or longitudinal correlates of behaviours present at each data collection time point. In the few studies that have examined correlates of persistence or change in challenging behaviour, there are no specific characteristics that emerge systematically as important, although adaptive skills or other aspects of ability are usually implicated.

In a seven-year longitudinal study of challenging behaviours in adults with an ID, individuals whose behaviour was perceived as more demanding at both time points were younger and less able than those whose behaviour was perceived as less demanding at both time points (Kiernan et al., 1997). Persisting severe self-injurious behaviour has been shown to be significantly predicted by younger age, higher stability of self-injury over the previous six months, and its topography (self-injury to the head) seven years earlier (Emerson et al., 2001b). Children with persistent stereotypies have been shown to have lower adaptive skills and more severe stereotypies five years earlier, compared to children whose stereotypies decreased over time. Persistent overall

behaviour problems showed a small association with a diagnosis of autism but, generally, were not related to age, gender, severity of problems in the past, or adaptive skills (Chadwick et al., 2004).

Taken together, these findings suggest that individuals with persistent challenging behaviours might be different, or perceived differently, from individuals who never exhibited challenging behaviours and those whose behaviours changed over time (either improved or deteriorated). The aim of the present study was to identify individuals with persistent challenging behaviours among a group of adults followed up over a period of 11 years, and investigate how the characteristics of these individuals were different 11 years earlier from those who had never exhibited serious challenging behaviours. Identifying the way in which those who persistently exhibit challenging behaviours differ from those who persistently do not exhibit serious challenging behaviours may enhance our understanding of the personal characteristics associated with the long-term maintenance of challenging behaviours.

In the present study, we investigated the chronicity of challenging behaviours using three different indices, which provide complementary information: persistence percentages, measures of association, and relative risk. Persistence percentages refer to the percentage of people identified as showing severe challenging behaviour at Time 2 among those who were identified with severe challenging behaviour at Time 1, an index used in other longitudinal studies (e.g., Emerson et al., 2001b; Turner & Sloper, 1996). While these percentages indicate which people have severe problems at both time points, measures of association provide an indication of the strength of the relationship in the measured challenging behaviours over time. The relative risk indicates the ratio of the proportions of those with severe challenging behaviour at Time 2 among those

who had severe challenging behaviour at Time 1 and those who did not. Therefore, it provides an index of the risk for persistent challenging behaviour.

Method

Participants

Interview survey schedules were completed for 58 adults who lived in group living arrangements on a residential facility in 1992 and 2003. These 58 participants were part of a larger service planning survey that was conducted in 1992 in light of the future relocation of all the residents to community settings. Eleven years later (2003), the survey was repeated on the 58 people who were still remaining in the residential facility.

The adults with an ID had a mean age of 45 years (range 23 to 83 years) in 1992 and 62% were men (n=36). By 1992, they had spent on average 12 years in the residential facility (range 4 to 22 years) and only one individual was detained through the criminal justice system on a formal hospital order. All 58 participants resided in hospital wards throughout the duration of the study. Based on the in-service assessment of the level of ID, the majority of participants were reported to have severe ID (n=46). A very small number of people had a diagnosed condition associated with their ID: three participants had a diagnosis of Down syndrome, and another three were diagnosed with autism. Twenty-three per cent of participants were experiencing epilepsy-related seizures at the time of the survey in 1992. Eleven participants were diagnosed with schizophrenia, three with depression, and one with unclassified psychotic condition at the time of the survey in 1992. Table 2.1 summarises the characteristics of the 58 participants in 1992.

Table 2.1. Characteristics of Participants in 1992

	n[1]	Summary Statistic
Mean age in yrs (sd)	58	45.26 (12)
Mean length of stay in yrs (sd)	57	16.39 (4.5)
Gender	58	Men: 36 (62%)
		Women: 22 (38%)
Degree of intellectual disability	57	Borderline: 2 (3%)
		Moderate: 9 (16%)
		Severe: 46 (81%)
Psychiatric Disorder	56	One or more disorders diagnosed: 15 (26%)
		No disorder present: 41 (71%)
Epilepsy	57	Present: 13 (23%)
		Absent: 44 (77%)
Vision	58	Normal: 55 (95%)
		Problematic: 3 (5%)
Hearing	58	Normal: 49 (84.5%)
		Problematic: 9 (15.5%)
Mobility	58	Mobility problems: 22 (38%)
		No mobility problems: 36 (62%)
Mean communication score (sd)	58	15.60 (6.96)
Mean daily living skills score (sd)	58	4.45 (3.09)
Mean sociability score (sd)	58	1.58 (1.49)

[1]Where n≠58, staff responses of 'do not know or not assessed' were set as missing values

Measures

Challenging behaviours were measured using the Individual Schedule of the Challenging Behaviour Survey (Alborz, Bromley, Emerson, Kiernan, & Qureshi, 1994). The rating scale consists of two parts. Part I includes information on the characteristics of the individual, such as demographic information, presence of syndromes, psychiatric disorders, epilepsy, sensory functioning, mobility, self-care skills, communication skills, stereotypical behaviours, and relationships with other people. Items in Part I are rated either on a categorical or an ordinal scale. The range of the ordinal scale varies for different items. For example, self-care skills (such as washing) are rated on a scale from 1 (independent washing) to 4 (completely dependent); understanding communication is scored on a scale from 1 (understands little or nothing) to 6 (understands information about things outside own immediate experience). Part II includes questions on four topographies of challenging behaviours: physical attacks on other people, self-injurious behaviour, destructive behaviour, and "other" difficult, disruptive, or socially unacceptable behaviour. Informants are asked to identify whether the behaviour in question is serious, present but a lesser problem, serious but controlled in this setting (e.g., by medication), or not a problem for the person. Appendix 1 includes a copy of Parts I and II of the Individual Schedule (Alborz et al., 1994).

Following previous research using this survey (Emerson et al., 2001b), challenging behaviour variables were dichotomised as serious/controlled and no/lesser challenging behaviour. Stereotypy (from Part I of the Individual Schedule) which was originally measured on an ordinal scale (all the time, daily, weekly, monthly, less frequently, never), was also dichotomised: on a daily basis versus less frequent stereotypical behaviour. A composite challenging behaviour outcome was also created by combining physical attacks, self-injurious, destructive and other disruptive

behaviour. Stereotypy was not included in this composite due to the fact that it was measured on the basis of frequency, whereas all other behaviours were assessed in terms of their severity as a management problem.

The Individual Schedule has been used in other longitudinal (e.g., Emerson et al., 2001b; Kiernan et al., 1997) and cross-sectional studies (Lowe et al., 2007) of challenging behaviours and has adequate inter-rater reliability (coefficients for Part I variables ranged from .67 to .89 in Emerson et al., 2001b; Kiernan et al., 1997, while average percentage agreement for the whole scale was 88% in Lowe et al., 2007).

Reliability. In the present study, the inter-rater reliability of the Individual Schedule was assessed by obtaining pairs of interview assessments for 14 people (24%) across the two data collection periods. Inter-rater agreement was calculated using correlation coefficients (Spearman rho for ordinal-level data) and percentage agreement (R for binary variables). Average inter-rater agreement on the Part I variables was rho: .83 (range .33-1) and R: 88.27% (range 75%-100%). Average inter-rater agreement on the challenging behaviour outcomes was 79.5%: 82.5% on physical attacks, 60% on self-injury, 90% on destructive behaviour, 65% on other disruptive behaviour and 100% on stereotyped behaviours.

Data reduction. To reduce the number of variables from Part I of the Individual Schedule to more meaningful composites, four subscales were created: daily living skills, sensory/motor problems, communication skills, and a sociability index. Individual variables which made up these subscales were rescaled, so that all items started from a score of 0, and reverse coded, if needed, to ensure that in all items the highest score indicated higher ability level. Then, they were summed to create the subscales. Daily living skills included nine items: continence, eating, washing, dressing, domestic skills, ability to self-occupy constructively, money handling skills, and

appropriateness of interactions with familiar and unfamiliar people. Sensory/motor problems included three items: vision, hearing, and mobility. Communication skills comprised three items on expressive and receptive communication. The sociability index included four items on group participation, friendships, and relationships with staff and other residents. Missing values in variables that made up the subscales were replaced by the individual's mean/median from the remaining variables. Higher scores in these subscales indicate a higher skill level (daily living skills range: 0 to 28, communication skills range: 0 to 9, sociability index range: 0 to 4). Internal consistency in the 1992 data was very good for three of the subscales (daily living skills Cronbach's α: .85; communication skills α:.83; sociability index α: .78) but not for the sensory/motor problems one (α: .11). This last subscale was not used in the analysis. Instead, the individual variables (hearing, vision and mobility) were used.

Procedure

A survey of all adults with ID in a residential setting was conducted to plan the services required for the future relocation of these people from the residential setting to community settings. The study was reviewed and approved by the Research and Development department of the Health Services Organisation which would manage the community placements of the participants upon their move out of the residential setting. The Individual Schedule was completed by an experienced rater during a structured interview with a member of staff who knew the person well. In 1992, interviews were conducted for 92 adults in a residential facility. In 2003, interviews were repeated for the 58 people who were still remaining in the residential facility (16 had died and 18 had been relocated to community settings).

Results

Data Analysis Strategy

Chronicity of challenging behaviours was examined by persistence percentages and a measure of association (Cramer's phi). To examine the associated risk of persistent challenging behaviours, we complemented these two measures with the relative risk, an index which compares the proportions of people with severe challenging behaviour in 2003 between those with severe challenging behaviour in 1992 and those without. Relative risk was calculated using the formula P_A/P_B , where a,b,c,d, stand for the number of people in the relative sub-groups (as shown in Table 2.2) and P_A and P_B are the associated probabilities (Table 2.2).

Table 2.2. Sub-Groups and Associated Probabilities

	2003		Probabilities
1992	Serious/controlled challenging behaviour	No/lesser challenging behaviour	
Serious/controlled challenging behaviour	a	b	P_A= a/(a+b)
No/lesser challenging behaviour	c	d	P_B= c/(c+d)

The characteristics of the individuals with persistent challenging behaviours were compared to those of individuals without severe challenging behaviour at both time points, using chi-square statistics or non-parametric comparisons (Mann-Whitney U test). The small sizes of the sub-groups whose behavioural ratings changed between

the two time points (i.e., their behaviour improved or deteriorated) did not allow for investigating any potential differences in the characteristics of these sub-groups.

Persistence of Challenging Behaviours

High persistence rates of challenging behaviour were present across the sample. Total challenging behaviour was rated as serious/controlled in 38 people in 1992. Thirty of these (79%) still presented with a serious/controlled problem in 2003. Persistence percentages were variable for each topography of behaviour: 70% for physical attacks, 47% for self-injury, 11% for destructive behaviour, and 59% for other disruptive behaviour, and 65% for stereotypy (see Table 2.3).

Table 2.3. Persistence of Challenging Behaviours over 11 Years[1]

	2003	
1992	Serious/controlled behaviour	No/lesser behaviour
Serious/controlled challenging behaviour	30 (79%)	8 (21%)
No/lesser challenging behaviour	12 (60%)	8 (40%)
Serious/controlled attacks	11 (70%)	5 (30%)
No/lesser attacks	9 (21%)	33 (79%)
Serious/controlled self-injury	7 (47%)	8 (53%)
No/lesser self-injury	7 (16%)	36 (84%)
Serious/controlled destructive behaviour	1 (11%)	8 (89%)
No/lesser destructive behaviour	9 (18%)	40 (82%)
Serious/controlled other disruptive behaviour	18 (58%)	13 (42%)
No/lesser other disruptive behaviour	13 (48%)	14 (52%)
	On a daily basis	Less frequent
Stereotypy on a daily basis	17 (65%)	9 (35%)
Less frequent stereotypy	6 (19%)	26 (81%)

[1] Percentages are based on row totals

The stability of challenging behaviour over time was examined further using two more indices: phi coefficients and relative risk (Table 2.4). Physical attacks, self-injurious, and stereotyped behaviours were found to be stable over time whereas destructive and other disruptive behaviours were not. The significant risk ratios for stereotypy, physical attacks, and self-injury highlight the increased risk of persistence of these behaviours for people who already had these behaviours in 1992, compared to those who did not. The relative risk for physical attacks was 3.21, indicating a 221% increase [$100\%^* (P_A-P_B)/P_B)$] in the probability of exhibiting serious physical attacks in 2003 for people with serious physical attacks in 1992 compared to people without serious physical attacks in 1992. The relative risk for severe self-injury was 2.87, indicating a 187% increase in the probability of exhibiting serious self-injury in 2003 for people who exhibited serious self-injury in 1992 compared to those who did not. Lastly, the relative risk for stereotypical behaviours 3.49 indicated a 249% increase in the probability of exhibiting frequent stereotyped behaviours for people who had frequent stereotyped behaviours in 1992 compared to those who did not exhibit them as frequently.

Table 2.4. Stability of Challenging Behaviours over Time and Associated Relative Risk

	Phi coefficient (*p* value)	Relative Risk [95% C.I.]
Total challenging behaviour	.201 (.125)	1.32 [0.89-1.95]
Physical attacks	.445 (.001)	3.21 [1.65-6.25]*
Self-injurious behaviour	.311 (.018)	2.87 [1.20-6.82]*
Destructive behaviour	-.070 (.596)	0.61 [0.09-4.21]
Other disruptive behaviour	.099 (.450)	1.21 [0.74-1.97]
Stereotyped behaviour	.474 (<.001)	3.49 [1.61-7.56]*

* significant at $p<.05$

The Characteristics of People with Persistent Challenging Behaviours

To explore further the differences between the participants who still had serious/controlled challenging behaviours after 11 years and those who persistently had lesser or no challenging behaviours, we excluded individuals whose behavioural ratings changed from 1992 to 2003. Table 2.5 presents all comparisons on 1992 characteristics between those who never had serious challenging behaviours and those who persistently had challenging behaviours. As there was only one person (see Table 2.3), whose destructive behaviour was assessed as serious/controlled at both time points, this topography was excluded from the analysis.

Table 2.5. Differences on 1992 Characteristics between Participants with Persistent Serious Challenging Behaviours and Those without Persistent Challenging Behaviours

	Persistent challenging behaviour		Persistent physical attacks		Persistent self-injurious behaviour		Persistent other disruptive behaviour		Persistent stereotyped behaviours	
	No (n=8)	Yes (n=30)	No (n=33)	Yes (n=11)	No (n=36)	Yes (n=7)	No (n=14)	Yes (n=18)	No (n=26)	Yes (n=17)
Gender (male)	3	18	18	7	21	4	6	10	15	10
Age (sd)	51 (15)	44 (12)	**47 (13)**	**38 (10)** [1]	**45 (11)**	**37 (14)**	47 (15)	47 (10)	46 (12)	42 (12)
Length of stay (sd)	17 (5)	16 (5)	17 (5)	15 (5.5)	16 (5)	15 (4)	16 (4.5)	17 (5)	16 (4)	17 (4)
Severe ID	7	25	25	9	28	7	11	16	19	15
Psychiatric disorder	1	11	6	4	10	1	1	6	5	4
Epilepsy (absent)	5	24	22	9	26	5	10	16	17	14
Hearing (normal)	7	25	28	10	30	6	13	14	23	13
Vision (normal)	8	29	31	10	34	6	14	18	25	15
Mobility (normal)	**0**	**22**	**14**	**9**	21	5	**6**	**15**	16	10

	Persistent challenging behaviour		Persistent physical attacks		Persistent self-injurious behaviour		Persistent other disruptive behaviour		Persistent stereotyped behaviours	
	No (n=8)	Yes (n=30)	No (n=33)	Yes (n=11)	No (n=36)	Yes (n=7)	No (n=14)	Yes (n=18)	No (n=26)	Yes (n=17)
Daily living skills (sd)	15.39 (10.26)	14.18 (6.18)	15.54 (8.22)	15.35 (5.48)	**17.36 (6.95)**	**11.20 (3.62)**	16.99 (8.83)	14.54 (6.03)	**18.72 (7.36)**	**11.43 (4.59)**
Communication skills (sd)	3.37 (3.29)	4.27 (3.08)	4.30 (3.30)	3.54 (2.77)	4.83 (3.09)	3.29 (2.93)	3.64 (3.27)	4.83 (3.09)	5.04 (3.09)	3.65 (3.00)
Sociability index (sd)	1.87 (1.88)	1.23 (1.43)	1.67 (1.57)	1.36 (1.43)	1.80 (1.45)	0.86 (1.46)	2.17 (1.64)	1.50 (1.54)	**2.07 (1.51)**	**1.00 (1.22)**

[1] Highlighted numbers indicate that the between-group difference is significant. See text for test result and p value

For physical attacks, individuals who persistently had serious/controlled behaviours at both time points were younger in 1992 (U=98, p=.023) and had fewer mobility problems ($\chi^2_{(df=1)} = 5.13$, p=.023) compared to those who persistently did not physically attack others. Similarly, individuals with persistent self-injurious behaviours were younger (U=59.5, p=.026) in 1992 and had lower daily living skills scores (U=51.5, p=.012). Individuals with persistent other disruptive problem behaviours were more likely to be fully mobile ($\chi^2_{(df=1)} = 5.72$, p=.017). Individuals with persistent overall challenging behaviours were more likely to be fully mobile ($\chi^2_{(df=1)} = 13.93$, p<.001). Stereotyped behaviours which persisted at a frequency of daily or more frequently over the 11-year period were more likely in those with lower daily living skills in 1992 (U=82, p=.001) and lower sociability skills in 1992 (U=129.5, p=.020). There were no differences between those with and without persistent challenging behaviours on gender, length of stay in the residential facility, degree of ID, presence of psychiatric disorder, presence of epilepsy, vision or hearing impairment, or communication skills.

Discussion

In this study, we presented information on the persistence of challenging behaviours in a group of adults with ID over an 11-year period. The findings suggested that physical attacks, self-injurious, and stereotyped behaviours persist over time and their earlier severity increases the risk of exhibiting these behaviours over 11 years. Although challenging behaviours were studied over a longer period than in the majority of follow-up studies, percentage persistence was generally in line with previous research. More specifically, physical attacks persisted in 70% of the participants who exhibited them in 1992, a level similar to that found for physical attacks in children (74%; Emerson, Robertson, et al., 1996) but somewhat lower to that found in young

adults (83%; Kiernan & Alborz, 1996), or adults in an institution (87%; Nøttestad & Linaker, 2002). In 2003, severe self-injurious behaviours were found in 49% of the people who had severe self-injurious behaviour in 1992. This was slightly lower than the 57% persistence percentage reported in a seven year follow up of adults (Emerson et al., 2001b), and also lower than the persistence percentages reported from longitudinal studies of younger people or children (72%-75%; Emerson, Robertson, et al., 1996; Kiernan & Alborz, 1996). The high persistence percentages found for destructive behaviours in other studies (above 70%; Emerson, Robertson, et al., 1996; Kiernan & Alborz, 1996) were not found in the present study (11%). One factor which might account for this discrepancy is the substantially older sample that participated in our study (56 years on average by 2003), although the association between age and persistent destructive behaviour could not be explored in the analysis. Frequent stereotyped behaviours were persistent in 65% of participants who exhibited them in 1992, a percentage also found in a longitudinal investigation of stereotypy in children (Chadwick et al., 2004).

The relatively high persistence percentages found for physical attacks, self-injury, and stereotyped behaviours were supported by the moderate correlations in the measurements of these behaviours over time, and the increased risk of exhibiting serious behaviour problems after 11 years, given serious problems in 1992. Participants whose behaviour problems were considered serious in 1992 were significantly more likely to exhibit persisting serious self-injury, physical attacks, and stereotypy (by about 200% or more) over 11 years.

Combining the information on chronicity of challenging behaviours coming from the three different indices, some interesting points emerge. The high persistence percentage found in the overall challenging behaviour composite (79%) was not

supported by the low correlation of these behaviours and risk ratio which was not significant at the 5% level (Table 2.4). The persistence percentage for other disruptive behaviours (48%) was accompanied by a near-zero correlation of these behaviours over time and a non-significant relative risk. On the other hand, the 47% persistence percentage of self-injurious behaviours was accompanied by a significant relative risk which indicated a 188% increase in the probability of persisting serious self-injury. The differences between these indices suggest that longitudinal studies might consider using more than one chronicity index systematically. In addition, while in the present study there were only two measures of challenging behaviours across a period of 11 years, future studies could obtain more robust stability indices by including a larger number of repeated measurements over the time period of the study. In the present study, the variation within each index (persistence percentage, correlation, and relative risk) for the different topographies of behaviour was lost when examining the overall challenging behaviour composite. This suggests that a composite measure of overall challenging behaviour is less informative than exploration of individual behaviours.

We also investigated the characteristics of individuals with persistent behaviour problems. Ideally, any such differences would have also been explored in the group of people whose behaviour improved or deteriorated in the course of 11 years. Unfortunately, this was not feasible due to the small number of individuals in these two sub-groups (see Table 2.3). Individuals who persistently engaged in physical attacks were younger in 1992 and had better mobility. Younger age was also found in people with persistent self-injurious behaviours, similar to the findings of a seven-year follow up of self-injury in a group of people who were 20 years younger than the participants in this study (Emerson et al., 2001b). The relationship between age and challenging behaviours is not always clear in longitudinal (Chadwick et al., 2004; Nøttestad &

Linaker, 2002) or cross-sectional investigations (Crocker et al., 2006), but there is some cross-sectional evidence of higher frequencies of challenging behaviours at younger ages which decrease as people get older and are rare after the age of 60 (Holden & Gitlesen, 2006).

In the present study, individuals with persistent self-injury also had significantly lower daily living skills in 1992. Although this is the first time this finding emerges from a longitudinal evaluation, it is consistent with evidence from cross-sectional studies of decreased ability levels in individuals who self-injure, either in the form of more severe ID level or decreased adaptive skills (e.g., Baghdadli, Pascal, Grisi, & Aussilloux, 2003; Borthwick-Duffy, 1994; Emerson et al., 2001a; McClintock et al., 2003; Lowe et al., 2007). The significantly lower skills in individuals with persistent self-injury in 1992, in combination with the persistence of this behaviour over time and the increased associated risk emphasise the need for intervention approaches which target skills required for everyday activities such as washing, dressing, eating, doing domestic activities and interacting with other people (e.g., Active Support; Chapter 3).

Similar to persistent self-injury, persistent stereotypy was associated with lower daily living skills in 1992, and with lower scores on the sociability index. Lower adaptive skills in persistent stereotypy have also been found in a longitudinal study of problem behaviours in children (Chadwick et al., 2004). Stereotypy has not yet attracted much research interest in persistence studies, but a meta-analysis identified this behaviour as more frequent in people with severe as opposed to mild ID (McClintock et al., 2003). Although in our study level of ID was not related to stereotypy, this could be due to the lack of variability in ID level as the majority of people were in the severe range.

Over extended periods of time, personal characteristics may not be informative about the maintenance of challenging behaviours. Personal characteristics and adaptive skills are relatively static. A 25-year longitudinal investigation of the changes in the skills of people with an ID suggests that after early adolescence changes in skills are rare (Beadle-Brown, Murphy, & Wing, in press). If the role of these static characteristics in the persistence of challenging behaviours is limited, then we need to examine longitudinally the role of environmental variables which relate to challenging behaviours. In particular, carer behaviours affect the maintenance of challenging behaviour and, in turn, challenging behaviours affect carer behaviour (Hastings, 2002b; 2005; Hastings & Remington, 1994a). Future research needs to address the role of carer behaviours in the long-term maintenance of challenging behaviour using longitudinal designs. For example, it might be predicted that those with persisting challenging behaviour have more stable environments, especially carers who persist in reinforcing challenging behaviours.

Chapter 3: Active Support: Development, Evidence-base, and Future Development

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Abstract

Active Support is a person-focused model of care for people with an intellectual disability who live in community-based small homes. The model aims to improve each person's quality of life by maximising participation in all types of activities of daily life with appropriate support from staff. In this review, we describe the basic characteristics of Active Support, its relationship with Normalisation theory and Applied Behaviour Analysis, and the evidence base for Active Support interventions. The methods available for training support staff and the latest developments in the Active Support model are presented. We conclude by discussing issues related to the adoption of Active Support by residential services and policymakers, and identifying dimensions that require further exploration. These future challenges include the translation of the Active Support model into real-world settings, and long-term maintenance of intervention effects.

Introduction

Active Support is a person-focused model of care for people with intellectual disabilities living with staff support in small community-based residential group homes. The main goal of Active Support is to increase the opportunities for participation in meaningful, age-appropriate activities for people with all levels of ability with appropriate support from staff. As a system for organising life in the group homes, Active Support has a strong philosophical basis that promotes an 'ordinary lifestyle' (King's Fund Centre, 1980). The Active Support model includes a system for organising activities and support for daily participation, a system for training staff to provide the right level of support to facilitate participation, and a system for promoting the residents' personal development through goal setting and skill learning. The basic technology was developed more than 25 years ago (e.g., Felce, 1989; Felce & Toogood, 1988; Mansell, Felce, Jenkins, de Kock, & Toogood, 1987), but the approach has been updated and refined (e.g., Jones et al., 1996, Booklets 1-6; Mansell, Beadle-Brown, Ashman, & Ockenden, 2005). New training methods and materials have been developed (e.g., Brown, Toogood, & Brown, 1987; Jones et al., 1996, booklets 1-6; Mansell et al., 2005; Toogood, 2004) for use in a number of applied studies across a variety of community residential service settings (Bradshaw et al., 2004; Jones et al., 1999; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Stancliffe, Harman, Toogood, & McVilly, 2007).

A review seems timely given the amount of development that has taken place and the level of interest shown in the UK and other countries. Our aims in preparing this review are threefold: (a) to describe Active Support, including its development, essential components, core concepts, and historical and current influences; (b) to review evidence from previously published studies on the effectiveness of Active Support; and

(c) to consider possible implications and future directions for Active Support for the research and service communities. In the sections that follow, we describe Active Support's philosophy as a model of care and its content as a system for organising life in community group homes. The structural components that make up Active Support are described in detail along with their functional equivalents from everyday life. The methods available for teaching staff of community residential homes to implement Active Support are briefly presented. We discuss the latest developments in the model, and the relationship between Active Support, Normalisation theory, Applied Behaviour Analysis and other current approaches. We review research evidence on engagement and staff support, which are the main outcomes used in evaluating the impact of Active Support. We describe the evidence available to date from evaluations of Active Support implementation in community residential settings. Finally, areas for future development of the model are identified.

What is Active Support?

A Brief History of Active Support

The fundamental components of Active Support were conceived, developed and evaluated between 1981-1986 in England's first small community home for persons with severe or profound intellectual impairments. A demonstration scheme, the Andover Project, was itself conceived, developed, and subsequently evaluated by a team of researchers. The Andover Project extended previous research in the Wessex region of England and was antecedent to a large scale program of deinstitutionalization throughout the UK during the 1990s. Active Support procedures were used during 1985-1990 in a separate demonstration project in which the Special Development Team (SDT; Emerson et al., 1987) assisted local service providers to develop small

community homes for persons with intellectual disabilities and challenging behaviours. The fundamentals of Active Support owe much to the insight of three researchers in particular: Jim Mansell, David Felce and Judith Jenkins promoted the concept of engagement as a major determinant of quality of life. They expressed emerging social policy (e.g. DHSS, 1971; DHSS, 1981) and policy guidance (e.g., King's Fund Centre, 1980) as practical outcomes defined by the concept of engagement (i.e., purposeful and meaningful interaction with the social and material environment). This was a significant contribution, both conceptually and practically. One of the early model's greatest strengths was its practical demonstration of how to focus attention on what people with intellectual disabilities *can* do and *learn* to do, as opposed to emphasising the restrictions imposed on them by their disability (Jenkins, Felce, Mansell, de Kock, & Toogood, 1987).

Active Support as a Philosophy of Care

Active Support is a philosophy of care which has at its centre the creation, support and maintenance of valued lifestyles expressed in terms of image, expectation, and the moment-to-moment lived experience of daily life. A core aim is to create opportunities and provide support and assistance for meaningful participation in the full range of everyday life-defining activity, irrespective of the degree of a person's disability (Jenkins et al., 1987; Mansell et al., 2002). Individually and collectively, staff involved in implementing Active Support are encouraged to value each person as being unique, capable of development and growth, and able to contribute toward enhancing the quality of their own lived experience and the lives of others. Staff are orientated toward a social model of support and encouraged to interpret their own role principally as planners, enablers, and teachers. Staff *plan* by organising the residential environment to promote to the fullest extent possible active participation by each person in the full range of

everyday life-defining activities. They *enable* by providing every person the support and assistance each requires on a moment-to-moment basis to participate in activities and by bridging the person's skills gap where necessary. They *teach* by differentially reinforcing behaviour that corresponds with active participation (what a person can already do) and use both incidental and formal teaching programs to establish new behaviour where necessary.

Active Support as a System of Planning and Review

A philosophy of active participation requires a technology for its implementation. Active Support provides, therefore, a multi-component paper-based system for planning, implementing, and evaluating: (a) the organisation of the residential environment, (b) individualised programs of care, support, opportunity, and learning over the short and medium term, and (c), subsequently, the collective experience of life in the home environment. Jenkins et al. (1987) provided the first full description of the multi-component planning and review systems that later came to be known as Active Support. Other early accounts can be found in Felce (1989), Mansell et al., (1987) and McGill and Toogood (1994).

Structural Components of Active Support

In this section, we describe the component systems of Active Support. Each component serves a particular function and works in conjunction with the others. There is a hierarchical nature in the component systems where implementation of the higher ones (such as Individual Plans) can be achieved by successful implementation of subordinate components (e.g., Opportunity Plans).

Routines and rhythms. Many activities of everyday life occur cyclically and most ordinary households have a system in place for ensuring everyday activities get done and everyone's interests are satisfied. In residential houses for people with intellectual disabilities, a similar system is developed to map these everyday activities and make the routines for each person individual, by involving residents as much as possible in the construction of activity plans and by taking account of individual preferences (Felce, Jones, & Lowe, 2002), thus avoiding institutional treatment of residents. Routines and rhythms are a hidden part of Active Support as activity mapping normally occurs when devising Activity Support Plans (see below). The utility of activity mapping is based on the notion that routines are functional (e.g., Saunders & Spradlin, 1991), and that it is the rigidity and ownership of routines that are potentially problematic rather than routines per se (Goffman, 1961). Mapping daily activities to key times of the day or week produces a framework of 'anchored' activity that has the effect of making the task environment more predictable (especially when many staff are involved), and brings a higher degree of autonomy and control to the house residents. Timetabling and individualising routines and rhythms of daily living means the routines belong to the people whose house it is rather than the staff whose job it is to facilitate them. Routines should be flexible, however, preserving the benefits of stability without introducing the constraints of rigidity. Flexible routines help ensure that important life sustaining activities such as shopping, cooking, and cleaning are carried out in a timely fashion and to an acceptable standard.

Activity Protocols. Activity Protocols are scripts that describe the way frequently occurring activities should be carried out. They are written in the form of task analysis, breaking down the activity into its individual components. Whereas task analysis has mainly been used to teach new skills (e.g., Tucker & Berry, 1980), the main aim here is

to ensure consistency in the way each resident experiences an activity – for example, the resident washes the dishes in the one way he or she knows, and this does not change according to which member of staff supports him or her – and to facilitate successful participation. Thus, the activity is broken down to as many steps necessary for the resident to accomplish at least a part of it (Mansell et al., 1987, p.202; Mansell et al., 2005, p.53). Activity protocols specify a frequency and standard for each activity and can include a risk assessment. Some protocols are person specific, such as a personal morning routine. Others are activity based and therefore more generic, such as mealtimes or washing dishes. Systematic use of the activity protocols by all staff and regular revision of the protocols helps residents to learn, from carrying out their routines consistently, to become gradually more autonomous and independent within and across their routines. Residents can also avoid learned helplessness from being corrected according to staff preferences for how to do an activity rather than its functional content.

Activity Support Plans. Activity Support Plans provide a method for: (a) flexibly planning activities over a 3-4 hour period, (b) allocating staff to provide support for persons taking part in those activities, and (c) tracking each person's lived experience. A common format involves the use of a printed page for each day or shift. Each page has a column for each person resident in the home. Beside each column is a space to identify which staff will support which person through a particular activity or sequence of activities. Regularly occurring 'anchor' activities for each person are pre-printed on the page at the time at which they are approximately expected to occur. Thus, the printed page for each day looks a little different to the others. Two additional columns list activities that ordinarily 'must' be done on the day and a menu of options for the day. Staff meet together briefly throughout the day to decide prospectively who will

support whom in which activities. They populate all of the white space between the anchor activities with incidental activities and activities drawn from the 'must do' and 'options' menu. Every resident has a range of activities available throughout the day and a member of staff available to provide the support they require. The procedure of selecting the activities to be included in the Activity Plans should include residents as much as possible, to make sure that activities reflect individual preferences. For residents with limited or no verbal ability, participation in the activity selection procedure can be facilitated using picture-based scheduling and manding procedures. Staff implement the plan alongside the residents and keep track using a simple tick chart called the Participation Index. The Participation Index spans one week at a time. Activities that occur on a regular basis are listed with space to add further activities as required. Staff record an event whenever a person takes part in a planned activity. Using these data (with each person acting as his or her own control) staff can monitor the rate and distribution of participation in activity within and across weeks and across activity domains. The benefits of prospective activity planning mean: (a) the task demand environment is made more predictable, controllable, flexible and capable of accommodating individual activity and scheduling preferences, (b) everyone knows what they should be doing, (c) everyone knows what everyone else should be doing, and d) there is a plan to come back to when things go wrong. Activity Support Plans help provide persons with intellectual disabilities with all of the benefits of routine without the constraints of rigidity. The Participation Index helps individual members of staff view each person's lived experience as a whole, and over time. Missed opportunities, over-exposure, or unevenly loaded schedules are quickly identified and corrected and the effects monitored. Additional learning and practice opportunities may be targeted through the medium and short-term goal planning systems described below.

Community contacts monitoring. An 'ordinary lifestyle' involves being part of the community and making use of community facilities. Community participation is important for an individual's social inclusion, a significant dimension of quality of life (Schalock, 1996). Community presence is the first step towards this goal and Active Support puts in place a system for monitoring frequency and duration of community access. Planned community activities are pre-printed on a form where staff later record whether the activity took place and its duration. Reviewing data for each person each week, staff look for stability and balance in each person's lived experience of community involvement - stability in the frequency and duration of community contacts over successive weeks, and balance in the distribution of community contacts over the days of the week and across different types of community involvement. Monitoring community contact in this way means staff get a picture of each person's overall lived experience of community involvement and can: (a) generate relevant targets for change, either directly or through medium and short term goal planning systems (see below), and (b) easily assess the impact of targets for increased or altered community involvement.

Individual Plans. Individual Plans provide an individualised focus and sense of direction over the medium term by prioritising a range of target outcomes and stating them in terms that are Specific, Manageable, Achievable, Realistic, and Timed (SMART). Outcomes, selected by the person and significant others, cover a range of life domains and address strengths and preferences as well as weaknesses and areas of need. A balance is struck between opportunities to engage in activities for which a person already has the skills, opportunities to learn new skills, and opportunities to try out new or unusual activities. Advantages that accrue from medium term goal planning are: (a) the person has a focus and sense of direction in his or her life, (b) staff involved

in mediating the plan are aware of the general direction of travel, (c) incidental goals may be targeted to complement or enhance the general direction of travel, and (d) the content of the plan can be assessed for intensity, relevance and balance.

Opportunity Plans. Opportunity Plans aim to create a context where residents develop their skills through regular practice and they can also be used to occasion activities a person can already do but seldom has the chance to perform. Opportunity Plans provide a semi-structured method of simultaneous multiple short term goal setting where no teaching method is specified. Staff work with behavioural objectives that specify: the person whose behaviour will change; the behaviour observed when successful; the level and type of assistance to be provided; the expected goal frequency; and a criterion for judging success. Up to 16 goals may be set on a weekly basis for each person. Learning opportunities are integrated into the natural flow of the day. A simple recording system is used to indicate whether the target behaviour occurs under the conditions specified or more help is required. Opportunity Plans provide a useful method for implementing medium term goals. Natural variability in the use of teaching procedures and activity materials may enhance generalization (Stokes & Baer, 1977). Simple audit procedures allow staff to assess the intensity, relevance and balance of the goals set, and probes provide a measure of maintenance and generalisation.

Structured Teaching Plans. Structured Teaching Plans specify long-term goals which are important to the person and cannot be taught any other way. A task analysis is performed to break the long-term goal down into a series of smaller, more manageable steps. A detailed Teaching Plan is then developed for each step in the task analysis. Teaching plans specify time, place, preparation, antecedent presentation, correct response, reinforcement, error correction, and recording method. Structured teaching: (a) provides a way for people to learn complex skills that they have been unable to learn

under less precisely defined conditions, and (b) helps staff develop skills useful in semi-structured and incidental learning opportunities. Behaviour acquired under tight stimulus conditions may require additional programming to secure maintenance and generalisation (Stokes & Baer, 1977).

Functional Aspects of Active Support Components

Figure 3.1 shows how the components of Active Support combine functionally to create opportunities for meaningful engagement in everyday life-defining activity. The area within the triangle represents the sum of a person's participation, social interaction, and learning. Components of Active Support form the sides of the triangle. The vertical axis labelled 'many -few' represents the amount of staff resource (number of opportunities) each part of the system consumes and the programming capacity that can be achieved. The axis labelled 'loose-tight' refers to the stimulus conditions under which participation and learning occur.

The single largest effect accrues from the base of the triangle. The volume and quality of incidental opportunities for engagement is influenced by: (a) staff's orientation toward a social model of support, (b) routine and rhythms, (c) Activity Protocols, (d) Activity Support Plans, and (e) data derived from the Participation Index and Community Log. Participation in activity creates incidental opportunities for learning that have at least two main advantages over more formally programmed support: They consume the least amount of staff resource, and occur under naturally occurring (loosely specified) stimulus conditions. Behaviour evoked or learned under these conditions is likely to contact naturally occurring reinforcement and to maintain and generalise (Stokes & Osnes, 1988).

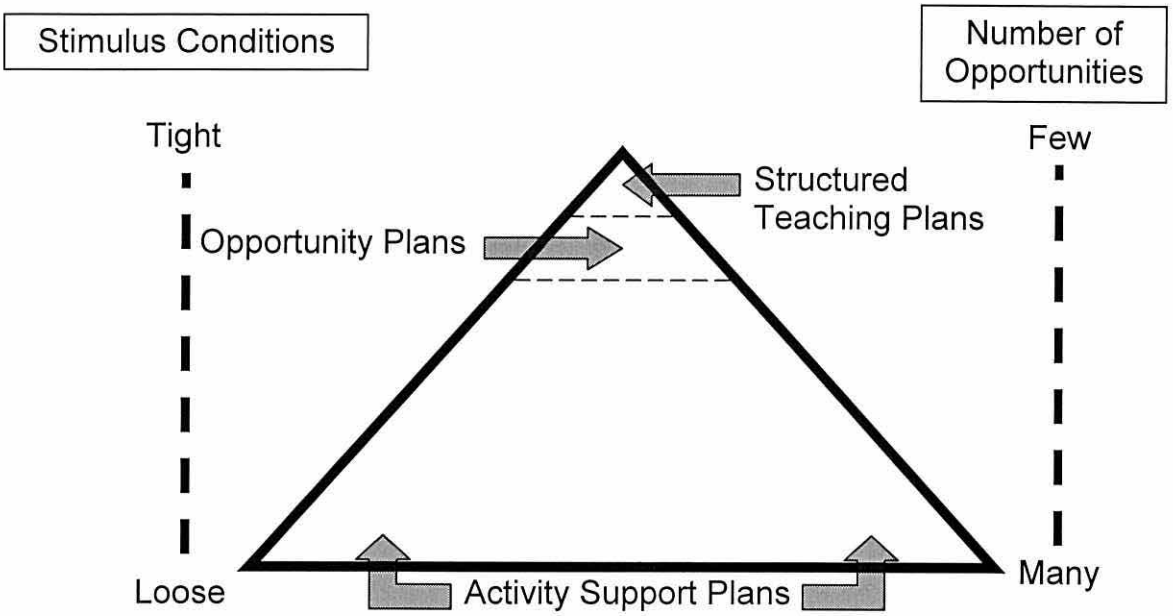

Figure 3.1. Active Support Functional Components.

Opportunity Plans add one degree of structure and are useful when a person cannot learn or access activities under incidental conditions alone. The approach consumes more resources than incidental learning but fewer than structured teaching. Staff can pursue a relatively large number of objectives concurrently. Opportunity Plans impact upon a smaller portion of the triangle than that associated with incidental opportunities, but it is larger than that for structured teaching. Because Opportunity Plans do not specify a teaching method, the situational context for each 'trial' is likely to vary. Proximity with natural contingencies of reinforcement and prospects for maintenance and generalisation are partially preserved. When persons cannot learn under semi-structured conditions, and the goal is important to them or others, staff may elect to devise a structured teaching plan. Structured teaching consumes a large amount of staff resource and the number of plans that can be run concurrently is therefore relatively small. Medium term goal plans sit at the tip of the triangle. They give shape

and direction to all programmed activity according to each person's unique strengths, aspirations and needs.

To summarise, the base level of Active Support planning involves planning daily participation and allocation of staff support to residents. This ensures participation in meaningful, age-appropriate activities and facilitates, with appropriate staff support, successful participation irrespective of the level of disability. At a higher level, medium term goals are set through Individual Plans and work towards these goals involves implementation of Opportunity Plans, Teaching Plans and Activity Plans either independently or in parallel. The existence of medium term goals acts as a common denominator in these components and provides a sense of direction for the life of the person with an intellectual disability. In this way, constructive and meaningful activity is combined with personal development, both necessary components of the productive well-being and, subsequently, the quality of the person's life (Felce, 1997).

Staff Training in Active Support

Staff are trained to implement Active Support in a two-day group workshop for all staff and managers and during on-site *Interactive Training*. The brief description of the workshops that follows is based on the training booklets developed by Jones and his colleagues (Jones et al., 1996, Booklets 1-6). The description of the Interactive Training is based on a model developed by Toogood (2004).

Workshop Training

Off-site training occurs in a one or two-day workshop. Materials for the workshop consist of six booklets , which present Active Support and its structural components –namely, Activity and Support Plans, Opportunity Plans, Teaching Plans, Individual Plans and ways of monitoring participation and community presence (Jones

et al., 1996, Booklets 1-6), a training video, a set of presentation slides and outline scripts for presenters (Jones et al., 1997). The aims of the workshop are: (a) to introduce a number of core concepts relating to the philosophy of care, (b) to describe the structural components of Active Support, and (c) to guide staff through customising the paper-based components of Active Support to the circumstances of the people whose home it is. For example, staff are guided through a mapping exercise to develop a timetable of weekly routines and rhythms for the home. They follow a number of prepared exercises leading to the identification of anchor activities with which to develop Activity Support Plans, and write the first set of Opportunity Plan goals.

On-site Interactive Training

Off-site workshop training is followed quickly by on-site *Interactive Training*. It is an integral part of the training designed to demonstrate how staff can work on a moment-to-moment basis when Active Support is implemented. Interactive Training is delivered individually to every member of staff in the house where the member of staff works. Thus, behaviour change procedures are bespoke and applied in the exact situational context within which behaviour change is expected to occur. Interactive Training is highly context–specific, tailored to the needs and skills of the staff-resident dyad. Trainers work with staff to find ways of supporting the resident(s) to participate in meaningful activities in a way that is most beneficial and enjoyable for everyone. The goal is to aid staff in finding ways of adjusting the level of support they provide according to the resident's needs, and to sustain participation by giving attention and further assistance when it is required (Felce, Jones, & Lowe, 2002). A detailed description of Interactive Training can be found in Toogood (in press).

Recent Developments in Active Support and the Training Model

The approach we have described so far is largely data-driven. Outcome data are collected continuously, concurrently and contemporaneously, providing a rich seam of important information about service effort (input) and each person's lived experience (output). An inherent assumption is that by carefully recording each person's lived experience staff have a valid way of monitoring the overall quality of the service they provide, and of recording progress and detecting the need for change or re-adjustment on an individual case (McGill & Toogood, 1994). A more recent training program was published by Jim Mansell and his colleagues in 2005. It is differentiated from the previously described training model in a number of ways: (a) emphasis is placed on person-centredness (the model is called "Person-Centred Active Support"), (b) the paper-based system of monitoring AS implementation and resident progress is removed, and (c) the training manual can be used by both teams and individuals (Mansell et al., 2005). These differences between training approaches reflect largely the different experiences that researchers and practitioners had while implementing Active Support in different parts of the UK Mansell et al. (2005) adopt a person-centred approach to reflect recent changes in British public policy (Department of Health, 2001), where Person-Centred Planning (PCP) is identified as the main strategy for supporting people with an intellectual disability. Active Support is proposed as a way of translating Person-Centred Planning into person-centred action (Mansell & Beadle-Brown, 2004).

Active Support implementation as described in the Mansell et al. (2005) training manual refers to activity timetables for the daily household activities (like the Activity Plans) while Opportunity, Teaching, and Individual Plans are omitted. The greatest difference though lies in the use of Participation Index and Community Logs. Mansell and his colleagues propose that by not relying exclusively on the paperwork for keeping

track of participation staff will realise that Active Support is about improving quality of life and not making paper plans. Worksheet forms are provided for staff to evaluate broader aspects of the organisational change that Active Support involves, and for staff and managers to evaluate and plan personal practice. Mansell et al. propose three alternative ways of monitoring quality (Module 3, 2005): (a) Look and See, (b) Develop Practice, and (c) Review. Under Look and See the suggestion is to spend time watching oneself or one's colleagues 'with a pair of fresh eyes' while keeping in mind these themes: preparation, presentation, graded assistance, resident success, and staff helpful style. Developing Practice refers to the need to identify areas for improvement which can be achieved through self-evaluation (either one is aware of one's weaknesses, or staff can videotape themselves while working and then watch their video), peer evaluation (buddy or mentor can give feedback after watching staff work) or supervisor evaluation (team leader spends time with one staff watching that person work). To improve the quality of active support Mansell et al. suggest staff obtain coaching from a mentor, or watch videos (of oneself or others), or use role-play.

In both main Active Support training models (Jones et al., 1996; Mansell et al., 2005) service managers are ultimately responsible for maintaining quality and sustaining the AS model. In the Jones et al. approach this is achieved through use of data collected on a daily basis and aggregated over the longer-term (Booklet 6, 1996), whereas in the Mansell et al. approach it is suggested that : "If they - senior managers - try to do this by asking staff to fill in forms about how many activities people have taken part in, they run the risk of inadvertently focusing attention on paperwork rather than on what is really happening in the relationship between staff and service user" (Module 4, 2005, p. 125). For this reason, Mansell et al. propose that the best way for managers to ensure service quality is to go into the house and see for themselves how

Active Support is working. If numerical data are required, there are four proposed items that can be checked on a Likert scale (1 = very weak to 5 = excellent):

1. people are engaged in meaningful activities and relationships and therefore developing in independence, choice and social-inclusion
2. senior staff are providing practice leadership by spending time with each staff member, giving feedback and modelling good practice
3. supervision happens sufficiently frequently and focuses on quality of support provided by each staff member
4. staff meetings happen sufficiently frequently and focus on the engagement of each resident in meaningful activities and relationships.

(Module 4; Mansell et al., 2005, pp.125-126)

Shifting the focus from paper-based planning probably reflects accumulated experience of implementing Active Support in services. To date, there are no empirical data that enable one to establish whether the implementation of Active Support is best done to include a detailed paper-based recording system or a model of implementation that does not include these. Anecdotally, the advantage of including paper-based recording mechanisms may be the availability of data for assessing each person's lived experience in terms of intensity, relevance and balance, but the disadvantage may be that staff time resources concentrate more in monitoring and less in implementation. The disadvantage of not including paper-based recording mechanisms may be the potential for biased estimations of Active Support effects, but its advantage may be that implementation of the model becomes more user-friendly. At present, neither of the two systems appears problem-free but it has to be noted that the proposed implementation methods have a somewhat different focus: continuous data collection allows the

evaluation of individual progress, whereas overall evaluation of organisational aspects and staff practice focuses more on the service as a whole.

Conceptual Issues

In this section we describe the relationship of Active Support with the theory of Normalisation and the science of Applied Behaviour Analysis to see how these two areas shaped the development of Active Support over time. We also briefly discuss the relationship between Active Support and other current approaches, namely Person-Centred Planning (PCP) and Positive Behaviour Support (PBS).

Active Support and Normalisation

The introduction and dissemination of Normalisation in the UK began around the time the Andover project was developing, and continued strongly for another decade and a half. The theory was influential in the UK impacting, for example, on the residential model proposed in the policy document *An Ordinary Life* (King's Fund Centre, 1980). This document declared people with intellectual disabilities "have the same human value as anyone else and so the same human rights…; living like others in the community is both a right and a need…; services must recognise the individuality" (pp.14-15) of people with intellectual disabilities. The impact was such that 'ordinary life' became almost synonymous with normalisation (Race, 1999).

A convergence of values was apparent among Normalisation, social policy, and the Andover model. The Andover model (and later Active Support) provided a practical demonstration of an organisational technology for the implementation and realisation of many competency and image-related Normalisation goals. Normalisation also continued to have an impact on the development of Active Support. Jones et al. (1996, Booklet 1), for example, drew on O'Brien's (1987) *Five Essential Accomplishments* when revising

and updating Active Support materials, and Mansell et al. (2005) described their whole approach as '*Person Centred Active Support*'. Active Support may be conceived as: a) an approach whose development was influenced by the dissemination of Normalisation theory, and b) an organisational technology that is suited to the implementation and accomplishment of Normalisation goals.

Active Support and Applied Behaviour Analysis

Whereas Normalisation and related concepts correspond with the core values of Active Support, the organisational technology within Active Support is derived directly from the field of Applied Behaviour Analysis (ABA). This combination of a conceptual framework with a systematic technology is an early example of 'rapprochement' between Normalisation and ABA as it was later described by McGill and Emerson (1992).

ABA is an applied science of human behaviour, based on the experimental analysis of behaviour (Skinner, 1953). It brings together a variety of empirically validated techniques and procedures derived from basic principles of behaviour, and it has a philosophical stance also, which is a mixture of scientific and social values as delineated, for example, in Baer, Wolf and Risley (1968). The philosophical and procedural aspects of ABA were well known to the originators of Active Support and have continued to influence its development ever since. Table 3.1 lists Active Support functions against Baer, Wolf and Risley's (1968) seven defining characteristics of ABA. The organisational structure, the approach to challenging behaviour, and the staff training model are the three areas of Active Support whose behavioural analytic dimensions are explored further below.

Table 3.1. The Dimensions of Applied Behaviour Analysis as Described by Baer, Wolf and Risley (1968) and the Way Active Support Relates to Them

Dimension	Definition	Active Support (AS)
Applied	Behaviour must be socially significant and important to the person or others.	AS addresses participation in the material and social environment as an observable and measurable indicator and determinant of Quality of Life, a construct which is important to most individuals and in which society has an interest.
Behavioural	Behaviour must be precisely measured and demonstrate whose behaviour changed	AS targets classes of staff and resident behaviour for change and systematically measures the extent and nature of change.
Analytic	The procedures used must demonstrate functional relations to the best degree possible, given the nature of the behaviour and context within which the procedures are being used.	Empirical research on AS has demonstrated functional relations between whole environment intervention and resident engagement and, for example, antecedent staff assistance and resident engagement.

Dimension	Definition	Active Support (AS)
Technological	Behaviour change procedures must be completely and precisely described so others can follow them.	AS procedures are described in training manuals and supporting materials.
Conceptually Systematic	Behaviour change procedures must derive from the basic principles of behaviour.	AS utilises a combination of procedures derived from behaviour analysis, e.g. differential reinforcement, task analysis, prompting, shaping, fading, data-collection and analysis.
Effective	Behaviour change procedures must result in large amounts of behaviour change.	AS studies have demonstrated statistically and clinically significant improvement in engagement and community participation.
Generality	Behaviour changes last over time, occur in a variety of settings and spread to other behaviour.	AS studies have demonstrated maintenance effects. AS procedures include continuous recording to track improvement and stability. AS data inform rate, duration, balance and distribution of engagement over time and across life-defining activities.

Organisational technology. The behavioural underpinnings of the organisational technology are evident in activity participation, learning, monitoring, and working with challenging behaviour. Incidental behavioural support and formal teaching programs rely for their success on the systematic application of techniques such as goal setting, task analysis, hierarchical prompting, shaping, fading, differential reinforcement, error correction, and data collection. Materials are presented so they become discriminative for participation (Mansell et al., 1987). Antecedent assistance follows a least-to-most hierarchical prompt sequence (Miltenberger, 2004), with an emphasis on nonverbal instruction (Repp, Barton, & Brulle, 1982). Assistance is varied according to need and decreasing assistance (Denchak, 1990) is used to increase resident independence over time by shifting stimulus control to more naturally occurring stimuli within the household. Maintenance is achieved by manipulating consequences. Staff attention, for example, is differentially weighted toward participation rather than lack of engagement or inappropriate behaviour, which indicates that in cases where staff attention functions to reinforce resident behaviours, the probability of participation behaviours should increase (Cooper, Heron, & Heward, 1987).

Active Support involves the collection of continuous data about individual people. Each person serves as his or her own control. Data are analysed, interpreted and displayed in ways consistent with a behaviour analytic approach to provide evidence of effectiveness. These data inform decisions about individual change. At a group level, data can be aggregated across the residential service to form the basis of clinical audit, a key aspect of clinical governance of care services (National Institute for Clinical Excellence, 2002). In the context of the British health care system these practices have been strongly emphasised since 1997 (Department of Health, 1997) as a way to ensure quality and accountability of services at a local level. The continuous and concurrent

nature of quantitative data generated by Active Support is especially relevant to good practice in clinical audit and provides continuous feedback for staff on service input as well as individual attainment.

Active Support and challenging behaviour. Eliminating challenging behaviour is not a primary aim of Active Support, although the model has been used in services to support people with seriously challenging behaviours (Emerson & McGill, 1993; Mansell, McGill, & Emerson, 2001). Properly implemented Active Support procedures can provide: (a) a rich source of data for functional descriptive assessment, (b) an excellent context for delivering functionally based multi-component behavioural interventions, and (c) data to help evaluate the impact of those interventions.

One of the main aims of Active Support is to create a whole learning environment through a combination of antecedent management and differential reinforcement. In an Active Support environment, for example, a person may be two or three times more likely to receive staff attention contingent on engagement than contingent on passivity or inappropriate challenging behaviour. In this way, Active Support can provide a way of contextualising procedures derived from ABA into the everyday lived experience of people with intellectual disabilities. The notion of creating 'helpful environments' for individuals whose behaviour may be experienced as challenging (McGill & Toogood, 1994) is consistent with Active Support as an ecological manipulation involving establishing and abolishing operations (Michael, 1982; Laraway et al., 2003) for challenging behaviour.

Challenging behaviour may be maintained typically by social positive reinforcement (e.g., social attention and access to tangibles), social negative reinforcement (e.g., escape from task demand or unwanted social attention) or automatic reinforcement, which may be positive or negative but its delivery is not

mediated by others (Carr, 1977; Iwata et al., 1994). Motivating operations momentarily establish or abolish stimulus events as reinforcing or punishing and evoke or abate behaviour associated with those events (Michael, 1982; Laraway et al., 2003).

The potential of Active Support in acting as a preventative intervention for challenging behaviours lies in the simultaneous modification of a large number of potential motivating operations without directly targeting the contingencies that maintain challenging behaviours. This may be particularly relevant where behaviour is multiply controlled. Where deprivation of attention functions as an establishing operation for challenging behaviour, an increased density of staff contact under Active Support may function as an abolishing operation and decrease the overall frequency of challenging behaviour associated with obtaining staff attention in the past. Similarly, increased independence, self-direction and personal autonomy that accrue from implementing Active Support may abolish deprivation of tangibles, such as activity materials and food, and reduce the occurrence of challenging behaviour for which deprivation of tangibles was an establishing operation. In the cases where challenging behaviour is maintained by escape from task demand, the aversive stimulus functions of task demand are modified in a number of ways. For example, under Active Support staff are trained to match the sequencing, scheduling, timing, and location of activities to each person's behavioural ability and individual preferences; to present task demands by carefully attending to the mode, pace, and complexity of antecedent instruction; to address task difficulty by breaking complex activities into smaller more manageable components; to present well timed verbal and nonverbal assistance as required; and to reinforce active participation in stages throughout the activity. In addition, Active Support seeks to establish a more attentive and responsive environment that 'listens' to functionally equivalent behaviour such as manding a change, more help or a break.

Tailoring the task demand environment to each person should mean escape contingencies are relevant less often and the frequency of behaviour associated with escape is reduced. Supported routines and structured teaching may also lead to greater mastery over skills and reduce the aversive properties associated with task complexity. Staff can then work systematically to assist persons to increase their tolerance for high-demand and to mand alternate behaviour. Finally, challenging behaviours maintained by automatic reinforcement, such as sensory stimulation, may also be influenced by improved access to activities and materials.

The above description of relationships between Active Support-induced changes in the environment and changes in challenging behaviour lies at a theoretical level. In a real-world application, a number of factors could interfere to affect this relationship. One of them has to do with staff. Staff behaviour has been implicated as a factor that facilitates maintenance of challenging behaviour (Hastings & Remington, 1994a), either by reinforcing it directly or failing to reinforce appropriate behaviours. In addition, staff may not be able to implement effective interventions (Hastings & Remington, 1993), even where they have received training in them, their beliefs are compatible with the intervention's principles, and they believe that interventions can be effective (Hastings, 1997). Moreover, the hypothesised interaction between the 'helpful environment' (McGill & Toogood, 1994) and the cause for some challenging behaviours might not take place. Research evidence suggests that improvements in the physical environment do not necessarily lead to a decrease in challenging behaviours (Emerson & Hatton, 1994). It is possible, for example, that automatically-maintained stereotypical behaviours may still be exhibited while the person is actively engaged in an activity. To understand how the 'helpful environment' which Active Support puts in place interacts with the causes of challenging behaviour, clinicians and researchers need to examine

any potential effects on challenging behaviours and then describe the changes in the function of the behaviours that Active Support may induce.

The staff training model. The training models in Jones et al. (1996) and Mansell et al. (2005) include group workshops and individually tailored on-site Interactive Training. Group workshops follow traditional instruction methods and are useful for imparting information and developing product. On-site training methods use direct observation and a combination of behaviourally derived methods (goal setting, task analysis, hierarchical prompting, shaping, fading, differential reinforcement, and error correction) to coach staff behaviour (Toogood, 2005a). It has been suggested that supplementing instructional methods with on-site training is more effective in producing staff behaviour change and in facilitating the transfer of the skills into everyday work (Anderson, 1987; Smith, Parker, Taubman, & Lovaas, 1992). This model also includes residential service users (Purcell, McConkey, & Morris, 2000; Smith et al., 1992) and achieves a high density of trained staff by massing the training experience over a brief period of time (Landesman-Dwyer & Knowles, 1987). On-site training draws on experiential learning theory, where learning is grounded on the 'here-and-now' experience (Kolb, 1984). It introduces variety into the learning experience mainly though varying the perspective (Fazey & Marton, 2002), for example, by verbally rehearsing or actually practising the experience of being supported in a particular way (Toogood, 2005a).

Active Support and Other Approaches: Person-Centred Planning and Positive Behaviour Support

Both Person-Centred Planning (PCP) and Positive Behaviour Support (PBS), approaches developed in the USA, share many similarities to the British model of Active Support. PCP is an umbrella-term that describes a number of approaches that

developed "systematic ways to understand a person with a developmental disability as a contributing community member" (Lyle O'Brien & O'Brien, 2002, p.3). The Normalisation principle and the accomplishment framework (O'Brien, 1987) provided the value-base for both Active Support and PCP (Jones et al., 1996, Booklet 1; Kincaid, 1996). Although there are many commonalities between the two approaches, an extensive description of those would be inappropriate as PCP includes many different approaches that focus primarily on the individual, whereas Active Support is one specific model developed, initially, with a clear focus on the individual resident of a small community home. So, whereas Active Support re-organises the operation of an existing structure (residential home) to meet individual needs, PCP gives emphasis to the individual needs and wants, and uses structures and services to meet these. Active Support begins by organising the person's daily life (going down to the moment-to-moment interaction between people: Activity and Support Plans) and then moving gradually to take a long-term view of the person's life course (with the Individual Plans). PCP begins by establishing the long-term goals and then proceeds to find ways of making them happen. By keeping the focus on the individual person, PCP does not put any constraints on the plans about the person's future; systems need to change to meet the person's needs and wants (Kincaid, 1996; Kincaid & Fox, 2002). On the other hand, Active Support's Individual Plans will be implemented though the Activity, Opportunity, and Teaching Plans which take place in the community home and, thus, will be naturally constrained by any resource limitations a service-provider might face.

Originators of the Active Support model view its relation to PCP approaches as complementary. Felce, Jones and Lowe (2002) suggested that when person-centred plans identify a need for an increase in the activity levels for one or more people in a home, then Active Support can be effectively used for this purpose. Mansell and his

colleagues (2005) have taken this one step further and re-labelled the model as 'Person-Centred Active Support' suggesting that PCP provides the 'bigger picture' and the plans can be translated into person-centred action through Active Support. Case study evidence from combining PCP approaches with Active Support (Sanderson, Jones, & Brown, 2001) suggests that Active Support can improve PCP by offering a systematic way for organising the implementation of plans, while PCP is probably more effective than Individual Plans in describing important goals for the person. Recent large-scale evaluations of PCP effectiveness indicate that PCP can facilitate gains in areas along dimensions also targeted by Active Support: daily activities, community involvement and more choice and autonomy (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Robertson et al., 2005). In fact, PCP and Active Support may also be related to ABA. Holburn (2001) discussed research paradigms that support the compatibility of PCP with the 'applied', 'behavioural' and 'conceptual' dimensions of ABA established by Baer et al. (1968).

This call for integrating Active Support in the PCP framework is somewhat similar to the call for co-operation between PCP and PBS, two approaches that have in common values, philosophies and, sometimes, techniques (Kincaid & Fox, 2002). In fact, Active Support has many similarities to PBS, in that they were both based on the principle of Normalisation and derived their technologies from the science of ABA. PBS's main aim is to improve the quality of life for all relevant stakeholders with a secondary aim of making challenging behaviour 'irrelevant and inefficient' (Carr et al., 2002, p.5). Both Active Support and PBS manipulate the environment in which the individual lives to bring about changes in the person's quality of life. The two approaches differ in their focus or not on challenging behaviour and the resulting assessment methods used to inform intervention. The reduction of challenging

behaviour has never been an explicit goal of Active Support. Rather, reductions in challenging behaviour are a desirable by-product of the increase in participation. In PBS, multi-component interventions are based on multi-component assessment procedures, which can include information obtained by interviews, rating scales, direct observations, development of hypotheses and sometimes hypothesis-testing using functional analysis techniques (Dunlap et al., 2000). Active Support focuses on increasing residents' level of participation in meaningful activities and, as implemented by service staff, utilises assessment methods which are not as extensive as the ones put forward as good practice in PBS. Complementing Active Support plans with PBS procedures for people for whom staff identify challenging behaviour as an obstacle to activity participation would likely facilitate the implementation of Active Support within a service. As we discuss below, challenging behaviour can affect both engagement in activities and staff behaviour. This highlights the need to increase effectiveness of Active Support in relation to challenging behaviour and PBS has demonstrated its potential to do just this (Kincaid, Knoster, Harrower, Shannon, & Bustamante, 2002).

Setting the Context for Evaluating the Effects of Active Support Implementation

The main outcomes examined in relation to Active Support effectiveness are resident engagement in meaningful activities (i.e., social interaction with staff, participation in domestic, personal, leisure, recreational activities) and staff support. The latter has been examined from the point of view of facilitating resident engagement (i.e., staff assistance), and also as an overall measure of staff contact. A secondary outcome measure for most studies has been residents' level of challenging behaviours. Engagement has been extensively used as an objective outcome indicating residents' quality of life. Beyond the field of intellectual disability, engaging in purposeful activity

relates to the 'productive well-being' dimension of quality of life (Felce, 1997) or personal development (Schalock, 1996) and even reflects social status, as 'having a busy lifestyle' is characteristic of the more privileged social groups in developed societies (Gershuny, 2005a, b). Real-time direct observation of resident and staff behaviours has been the main methodological tool for assessing Active Support implementation and rating scales have been used to assess residents' ability level and challenging behaviours.

If Active Support is to affect resident engagement, we would expect to see some evidence from existing research of relations between resident engagement and staff support. Resident engagement and staff support are outcomes that have been extensively assessed in the literature evaluating the effects of moving people with intellectual disabilities from hospitals to community-based accommodation. In a review of 46 studies, Emerson and Hatton (1994) found considerable variation in these outcomes within each type of accommodation although, on average, resident engagement was higher in community-based small houses (about 48% of the time) than in hostels or special units (25%) or hospitals (14%). The same trend was apparent for staff support: 15%, 9% and 4% for community homes, hostels and hospitals respectively. The researchers suggested that about 52% of the variation in resident engagement was accounted for by staff assistance (Emerson & Hatton, 1994). The effects of deinstitutionalisation on challenging behaviour were less clear and seemed to vary depending on the method of measuring behaviours (rating scales versus direct observations). The conclusion was that the move to a more enriched physical environment is not necessarily accompanied by a reduction of challenging behaviour (Emerson & Hatton, 1994; Hatton & Emerson, 1996).

Independent of Active Support research, a number of studies have examined the factors that determine resident engagement and staff support. Engagement has been found to be strongly related to residents' ability (Felce & Emerson, 2001; Felce & Perry, 1995; Felce & Perry 2004; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003), to be significantly predicted by ability skills and staff attention (Felce, Jones, Lowe, & Perry, 2003), by more staff positive contact, and living in a community setting (Hatton, Emerson, Robertson, Henderson, & Cooper, 1996). Participation in community outings has also been directly predicted by more scheduled activity and indirectly by higher cognitive skills (Hatton et al., 1996) whereas, after controlling for adaptive and challenging behaviours, engagement in social activities has been found to be predicted by fewer hours of planned activities (Felce, Lowe, & Jones, 2002a). Studies that have taken into account adaptive skills and challenging behaviour still report a significant effect of staff attention on resident engagement (Felce et al., 2002a; Perry & Felce, 2005), and residents' engagement in domestic activities (Felce et al., 2002a). In addition to staff assistance, the Felce et al. (2002a) study found that overall engagement was also predicted by the size of the house (more residents) and the internal organisation of the care environment. Domestic engagement was negatively predicted by staff:resident ratios and percentage of staff with formal care qualifications (Felce et al., 2002a).

Staff support and residents' adaptive skills, are either unrelated (Felce & Perry, 2004), or related in a complex way. For example, Felce et al. (2003) reported a small but significant prediction of staff attention by an interaction between adaptive skills and challenging behaviour (higher adaptive skills and low challenging behaviours) and by the internal organisation of the care environment. Felce, Lowe, and Jones (2002b) found that staff attention and assistance were both predicted by the range in measured adaptive skills (more homogeneous ability groupings) and staff:resident ratios but that higher

levels of qualified staff had a negative impact on assistance. Residents' higher cognitive ability and services' less institutional treatment (i.e., treating residents as a group and not as individuals, a management practice characteristic of institutions) were shown to predict indirectly staff assistance and positive contact which were also directly predicted by more hours of scheduled activity and being in a specialised service (Hatton et al., 1996).

In conclusion, research evidence suggests the presence of complex relations between resident engagement and staff behaviours. Apart from the impact of ability and in addition to other environmental/service characteristics, resident engagement seems to be associated directly with staff behaviours, which, in turn, are associated, either directly or indirectly, with resident characteristics (ability and challenging behaviour). These relationships set the context for the evaluation of the effects of Active Support.

Evidence Base for Active Support

In the two sections that follow, we describe in detail the outcomes of studies that directly measured the impact of Active Support on resident and staff behaviours. We also present some outcomes from studies that investigated various aspects of quality of life or community living. These outcomes were selected because they relate to Active Support and they add a different perspective to the evaluation outcomes.

Evaluation Studies of Active Support

Resident engagement and staff support are examined below in more detail in studies that have directly evaluated Active Support effectiveness. Table 3.2 presents information on these studies and Table 3.3 presents the percentage of time residents were observed engaged in activities and in receipt of staff contact. As the Active Support evaluation studies extend over a period of about 20 years, the outcomes were

not all defined in the same way. For example, the Andover project defined staff contact as Instruction and Physical Guidance (Table 3.3), while Jones et al. (2001b) measured total staff attention and assistance, among other staff behaviours.

Initial evidence came from two early clinical projects: the Andover project (Felce, 1989) and the Special Development Team (SDT; Mansell et al., 2001; McGill & Mansell, 1993; McGill & Mansell, 1995). The goal of both projects was to create residential placements for people who were either moving from the hospital to the community (Andover) or whose challenging behaviour required the development of specialised services to maintain them in the community (SDT). Data from these studies on resident overall engagement and staff contact are presented in Table 3.3. In the Andover project, increased resident engagement was found in house residents compared to people still living in institutions while staff in homes were observed to interact more with the residents using instruction and physical guidance (Felce, de Kock, & Repp, 1986; Felce & Repp, 1992). A follow-up on 10 of the initial 12 people two years after the move into homes showed that engagement remained at high levels (Saxby, Felce, Harman, & Repp, 1988). However, there was a significant decrease in staff contact (of about 5 to 8%; Saxby et al., 1988) bringing the overall levels of contact to 10% of the time or below (Table 3.3). The Special Development Team collected data on 13 people over time and found that there was a significant increase in participation in meaningful activities and staff contact after the move into the community (Mansell et al., 2001; McGill & Mansell, 1993).

Table 3.2. Studies that Have Evaluated the Active Support Model

Study	No of residents	Design/Methods	Study goal	Observational measures and rating scales
Andover Study; Felce, 1989	12	Observations pre- (2), post-move (2) and at follow-up (2 years after move)	Evaluate the effects of moving people from hospitals to community houses that operated using- what was later called- Active Support (AS)	Resident engagement in leisure, personal, domestic, teaching activities and in interaction with staff. Resident engagement in inappropriate activities. Staff behaviour as antecedents and consequences to resident behaviour.
Special Development Team (SDT); Mansell et al., 2001	13	Multiple time-series observations (9 data points between 1987 and 1991)	Develop community services for people with serious challenging behaviours. AS principles are found in the team's operational orientation	Resident participation in leisure, personal, practical activities. Challenging behaviour Staff contact

Study	No of residents	Design/Methods	Study goal	Observational measures and rating scales
Jones et al., 1999	19	Multiple baseline observations: pre (10), post-training (10) and follow-up (at 6 and 12 months after end of training)	Evaluate AS using an experimental design	Resident engagement in non-social (i.e. personal, domestic) and social activities. Challenging behaviour. Staff contact.
Jones et al., 2001a	188	Observations pre- (3) and post-training (3)	Compare AS implementation when training is researcher-led, researcher-supervised and independently delivered by service managers	Resident engagement in non-social (i.e. personal, domestic), social activities, and challenging behaviour. Index of Participation in Domestic Life (Raynes et al., 1994); Index of Community Involvement (Raynes et al.,1994). Staff verbal and non-verbal assistance, and contact.

Study	No of residents	Design/Methods	Study goal	Observational measures and rating scales
Mansell et al., 2002	23 (Control group n=26)	Waiting list control group, observations at pre- and post-training	Evaluate AS in residential services as provided by a charity	Resident engagement in meaningful activity. Active Support Measure (Mansell & Elliott, 1996). Behaviour Development Survey (Conroy et al., 1982).
Bradshaw et al., 2004	11 (Control group n=11)	Control group, observations at pre- and post-training	Replicate findings from previous studies using a control group	Resident activities. Contact with staff. Challenging Behaviours.
Stancliffe et al., 2007	22	Observations at pre- (6), post-training (6) and follow-up (3 to 9 months after end of training)	Replicate findings from British studies and evaluate AS implementation in Australia	Resident engagement in social and non-social activities and staff help. Index of Participation in Domestic Life (Raynes et al., 1994); Index of Community Involvement (Raynes et al., 1994); Inventory for Client and Agency Planning (Bruininks et al., 1986).

Table 3.3. Levels of Overall Resident Engagement in Activities and Contact from Staff Before and After Active Support

Study	Resident engagement		Staff Behaviour[1]		Follow-up	
	Pre	Post	Pre	Post	Engagement	Staff contact
Andover Project (data from Felce, de Kock, & Repp, 1986; Felce & Repp 1992; Experiment 1; Follow up: Saxby et al., 1988, *n*=10)	23% (while in institutions)	House 1: 51% House 2: 56%	Intruction:~1% Physical Guidance: ~0% (while in institutions)	Instruction: House 1:19.8% House 2: 11.3% Physical Guidance: House 1: 5.2% House 2: 3.2%	House 1: 44% House 2: 46%	House 1: 9% House 2: 10%
SDT (Mansell et al., 2001)	14% (institutions)	Sig. increase (*t*= 4.62, df=12, *p*=.005)[2]	Contact: 1.6% hospital wards 12.7% hospital units	Contact range: [13.2%-42.5%]	No follow-up	

Study	Resident engagement		Staff behaviour		Follow up	
	Pre	Post	Pre	Post	Engagement	Staff contact
Jones et al., 1999	33.1%	53.4%	Contact: 17.5% Assistance: 5.9%	Contact: 31.8% Assistance: 23.3%	57.2%	Contact: 28.2% Assistance: 16.0%
Jones et al., 2001b	46.7%	54.6%	Total attention: 14.9% Assistance: 7.5%	Total attention: 14.0% Assistance: 14.6%	No follow-up	
Mansell et al., 2002	7%	33%	ASM[3]: 50%	ASM: 66%	No follow-up	
Bradshaw et al., 2004	16.6%	26%	Contact: 16.7%	Contact: 21.2%	No follow-up	
Stancliffe et al., 2007	42.46%	49.54%	Help: 7.27%	Help: 11.42%	53.81%	13.56%

[1] Staff contact behaviours were defined differently in each study
[2] Overall resident engagement: 28%, based on n=11 (McGill & Mansell, 1993)
[3] ASM: Active Support Measure; Mansell & Elliott, 1996

In the first experimental evaluation of Active Support, five community homes participated in a multiple baseline design with 19 residents observed 10 times for 2 hours each time in their homes before and after the Active Support training, while one 2-hour observation was obtained 6 and 12 months after the end of the training. The observations suggested a significant increase in resident engagement in domestic activities within each house (Jones et al., 1999). Staff behaviour was measured either as total contact or staff assistance, which are behaviours that directly facilitate resident engagement. Staff assistance increased significantly within each of the five houses and staff contact increased in four of them. The data presented in Table 3.3 reflect average times across all five houses. There was no change in resident social engagement and there was no statistical comparison of the follow-up levels for engagement and staff contact and assistance. Pre-post change in staff assistance was related to change in engagement (rho = .84), indicating that increases in staff assistance were related to increases in resident engagement. Changes in staff assistance were inversely related to residents' adaptive skills (rho = -.77), which suggests that more assistance was available for the least able residents. Similarly, changes in engagement were inversely related to adaptive ability (rho = -.71), which indicates that less able residents showed greater improvements in their engagement. Staff assistance and contact were positively related to residents' ability scores before Active Support training (rho = .58 and .67 respectively) but this was not the case after the training (rho = -.26 and .02 respectively). This finding suggests that, whereas before Active Support increased staff contact was more likely to be available to the most able residents, after Active Support receipt of staff contact had nothing to do with how able a resident was. Most significantly, the likelihood of resident engagement occurring given the presence of

staff assistance increased after Active Support training (Felce et al., 2000), indicating that staff behaviours had become more effective in eliciting resident engagement.

In the subsequent larger-scale Active Support evaluation (n=188), Jones and his colleagues (2001a) compared outcomes in houses where Active Support training was delivered primarily from researchers (apprenticeship group), primarily from service managers with the researchers' help (supervision group), and from managers independently (independent group). It was found that there were no significant changes in the houses where managers delivered the training independently but in the other two groups there were significant increases in staff use of verbal instruction and non-verbal assistance, resident engagement in domestic activities, and more generally their non-social activities. The data presented in Table 3.3 are drawn from Jones et al. (2001b) where results are presented grouped for the apprenticeship and supervision groups (n=106). The significant increase in participation in domestic activities was also reflected in the Index of Participation in Domestic Activities (Raynes et al., 1994) and there was a significant increase in the reported type and frequency of social activities and the type of community activities (Jones et al., 2001b). Residents' adaptive skills were strongly correlated to engagement levels both before and after Active Support training (rho = .75 and .70 respectively) and moderately inversely related with the progress observed in engagement in domestic activities (rho = -.32). These findings indicate that, although the level of ability relates to the extent of engagement, increases in engagement in domestic activities were more likely for the less able residents after the introduction of Active Support. Changes made in a composite measure of staff attention were related with changes observed in residents' engagement in social activities (rho = .79), but not domestic activities, while changes in staff assistance (verbal and nonverbal behaviours) were related to changes in resident total engagement

(rho = .40), engagement in social interactions (rho = .28) and strongly related to changes in engagement in domestic tasks (rho = .64). Therefore, it seems that an increase in attention from staff is important for subsequent increases in the amount of time a resident engages in social activities. An increase in the more specific assistance behaviours seems to be important for increases in the amount of time residents engage in domestic tasks. Interestingly, changes in staff assistance were inversely related with residents' adaptive skills (rho = -.35) whereas there was no association between adaptive skills and staff assistance before the Active Support training, which indicates that even though staff provided assistance to all residents, after Active Support they increased the amount of time they spent assisting the least able residents.

In terms of the probability of residents' overall engagement given staff verbal and nonverbal assistance, a significant increase in the odds of engagement given nonverbal assistance was demonstrated for the apprenticeship group in the Jones et al., 2001a study (Smith et al., 2002). This finding indicates that after Active Support training staff's nonverbal assistance became more effective in eliciting residents' engagement. The effectiveness of nonverbal assistance in increasing engagement was also seen in the group of least able residents and those with autistic-type symptoms, whereas there was no increase in the odds of engagement with either verbal or nonverbal assistance for those residents with challenging behaviours (Smith et al., 2002).

In the first study to include a waiting-list comparison in a group design, Mansell and his colleagues (2002) evaluated the effects of Active Support training that was provided to the staff of 23 residents by another agency. The researchers observed an overall measure of engagement and they found that this increased significantly pre-post within the intervention group although there was not a significant difference between

the groups after the training. The Active Support Measure (ASM; Mansell & Elliott, 1996) is a 15-item observational measure that rates the quality of staff support, with items such as age-appropriateness of activities and levels and type of staff contact. Mansell et al. (2002) reported a significant pre-post increase in the ASM scores within the intervention group (see Table 3.3 for means). Compared to the waiting list control group, ASM scores were also significantly higher in the intervention group after the training, suggesting higher quality of staff support. A significant increase in adaptive skills was found in the intervention group. Bradshaw and her colleagues (2004) also used a comparison group and found a significant increase in levels of activity engagement for the intervention group. There was also an increase in levels of staff contact in the intervention group although the between-groups difference was not significant. Bradshaw et al. found that there was no significant relation between changes in staff contact and resident engagement ($r = .14$) and that the largest increases in engagement were observed in the two most able house residents.

In an Australian evaluation of Active Support, Stancliffe and colleagues (2007) found an increase in resident engagement and staff help in five homes that were observed before (pre), after training (post) and at follow-up (see Table 3.3 for means). Changes in staff help and resident engagement were strongly related between pre and post ($r = .73$) and between pre and follow-up ($r = .53$). Adaptive skills were not associated with changes in engagement at the end of the training or at follow-up, indicating that Active Support effects did not differ for residents of different ability level (Stancliffe et al., 2007). Comparisons made on data from rating scales suggested a significant increase in reported domestic and community activities at follow-up, and a non-significant increase in adaptive behaviour ratings (Stancliffe et al., 2007). It is noteworthy that in one of the five houses of this Australian study, both resident

engagement and staff help were observed at decreased levels post-training (but not at follow-up), which Stancliffe et al, attributed to a partial implementation of the Active Support model within that house -- possibly due to the lack of managerial involvement with Active Support.

The effects of Active Support on residents' challenging behaviours are somewhat less clear than the results for engagement behaviours. For the residents of the first (n=6) of the two houses participating in the Andover project self-stimulatory behaviours were observed for 20% of the time, which was higher than the comparison group in the institution and this same group moved into the second house (Felce & Repp, 1992, Experiment 1). Saxby et al. (1988) reported a decrease in inappropriate behaviour over a two-year period from 14% to 4% (n=10), whereas the levels of stereotyped behaviours for 4 of the residents in the first house remained at the same levels (29%, and two years later 31%). The SDT reported a non-significant decrease in minor (mainly stereotypy) and major challenging behaviours (29% to 16% and 9% to 4% respectively) for the 13 residents they observed but these researchers suggest caution in the interpretation of the results. Specifically, both minor and major challenging behaviours were greatly variable and the inter-rater reliability for major challenging behaviours was low as a result of the low frequencies at which these behaviours were observed and the unsuitability of the coding system (momentary time sampling at 20-sec intervals) for capturing them (Mansell et al., 2001). Jones et al. (1999) did not report the outcomes of their observations on challenging behaviour because of the low frequencies which affected inter-rater reliability, but Jones et al. (2001a) reported non-significant changes in overall challenging behaviours in their three groups (apprenticeship group: 21.2% to 18.6, supervision group: 13.5% to 14.6%, and independent group: 13.2% to 13.6%). Jones et al. (2001a) suggest that the

composite score used for challenging behaviour consisted mostly of stereotypy. Bradshaw et al. (2004) reported a significant increase in challenging behaviour for the intervention group (pre: 8.5% to post: 20.6%) which they attributed mainly to increases in stereotypic behaviours. Using a rating scale to assess challenging behaviours, Stancliffe et al. report no significant changes in challenging behaviour in their research.

In summary, studies that have evaluated the effects of Active Support in community houses show that resident engagement in meaningful activities of daily living increases significantly along with the amount/type of support residents receive from staff. With the exception of one study (Bradshaw et al., 2004), most studies have demonstrated that changes in staff behaviour are closely related to the observed changes in resident engagement. There is some evidence to suggest that Active Support is more beneficial for the least able residents (Jones et al., 1999; Jones et al. 2001b; Smith et al., 2002), although the finding has not always been replicated (Bradshaw et al., 2004; Stancliffe et al., 2007). The evidence regarding the effects of Active Support on residents' challenging behaviour is inconclusive so far, although there is some evidence to suggest improvements in adaptive skills (Mansell et al., 2002; Stancliffe et al., 2007).

Indirect Evidence Related to Active Support

In this section, we present correlational data from studies that have used two rating scales that relate to Active Support: the Active Support Measure (ASM; Mansell & Elliott, 1996) and the Residential Practices Working Scale (RSWPS; Emerson, Reeves & Felce, 2000; Lowe, Felce, Perry, Baxter, & Jones, 1998). The ASM is an observational rating scale of the nature and quality of staff support (Mansell et al., 2002). Inter-rater reliabilities on the measure have been reported above .95 (correlations coefficients; Mansell et al., 2002; Mansell et al., 2003) with internal consistency .92 (Cronbach's α; Mansell et al., 2003). In a study of 343 adults in residential

accommodation, the ASM total score was found to have near zero correlations with a number of measures: staff turnover, length of service, Active Support training, management development, seniority, staff:resident ratios, and total number of staff in employment (Mansell et al., 2003). Staff support, as measured by the ASM total score in this study, was not predicted by any of these staffing or training measures, but it was predicted by residents' younger age and higher adaptive skills scores (Mansell et al., 2003). ASM total scores did significantly predict resident engagement in activities (Mansell et al., 2003). Although the above data could suggest that improvements in staff skill and residents' engagement levels can happen independently of staff and service characteristics, the lack of a correlation between Active Support Training and ASM total scores is somewhat puzzling, given that implementation of Active Support requires staff training. It would be interesting to examine the extent to which ASM scores relate to other observational measures of staff behaviour, such as the ones used in other evaluation studies (e.g., Jones et al., 1999; Jones et al., 2001a). In addition, some of the ASM items (e.g., teaching embedded in activities, specific written individual programmes in routine use) measure directly the presence of structural elements of Active Support, which could add an important dimension to the Active Support effectiveness literature that has so far evaluated programme effects by measuring outcomes and assuming that the procedures (e.g., the paper-based system) were largely in place in the houses.

The RSWPS is a questionnaire developed to measure the presence of operational procedures that relate to individual or person-centred planning, behavioural assessment and teaching, planning of daily/weekly activities, arranging staff support for resident activity and staff training and supervision (Lowe et al., 1998). There are no psychometric characteristics available for this measure. Researchers have reported this

questionnaire as measuring the extent of 'Active Support implementation' in the care environment (Robertson et al., 2001). RSWPS total scores were reported to be a significant predictor of staff attention after taking into account residents' ability and staff:resident ratios (Felce et al., 2003), whereas RSWPS subscales were reported to correlate with residents' expressed satisfaction with their accommodation, their day activities and the amount of choice they are offered (Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001). In addition, the RSWPS subscales that measure staff support, support to staff and activity planning have been related to the presence or absence of a person with or without intellectual disability in the resident's network of social relationships (Robertson et al., 2001). Although some of the dimensions measured by RSWPS are similar to Active Support evaluation outcomes (e.g. activity planning, staff support), it is not clear from the existing studies how this measure could be used to directly evaluate Active Support implementation. However, the scale has been used to describe the level of internal organisation of a service in preparation for Active Support training and implementation (Jones et al., 2001a).

Discussion and Future Directions

In this paper, we described the development of the Active Support model over the last 25 years and the way this can be implemented in residential services through staff training. Following the research evidence on the beneficial effects on resident participation levels and the amount/type of assistance they receive from staff, a number of issues emerge that could provide directions for future research. The first direction relates to service adoption of Active Support. Despite the fact that the model was developed more than 20 years ago, uptake of Active Support in British residential services has been quite limited. Active Support is not the only example of an intervention with limited impact on policy and service practice. Within the research

field there is mounting evidence on the effectiveness of ABA-based approaches to treating challenging behaviour (e.g., Grey & Hastings, 2005), but within services written behavioural interventions are the least frequently used approach (Emerson et al., 2000). The discrepancy between research findings, policy and practice is in contrast to the current move to employ evidence-based practices in services. Currently, there is a lack of agreement among intellectual disability researchers on the type of evidence that is indicative of effectiveness (e.g., Beail, 2005; Emerson, 2006; Lindsay, 2006; Sturmey, 2005; Sturmey, 2006), given the ethical and methodological difficulties in using randomisation procedures in intellectual disability research (e.g., Oliver et al., 2002). The development of criteria for the type of methodology used to generate evidence and for the interpretation of evidence constitutes a significant first step in the direction of constructing an evidence base before moving on to addressing communication between the research community and services through dissemination of findings, user-friendliness of intervention protocols and guidelines and training of service staff (Corrigan, Steiner, McCracken, Blaser & Barr, 2001).

Outside the research field, the extent of the use of Active Support is less clear. In the absence of a study mapping offer and use of Active Support in the UK and abroad, it is assumed that personal choice and regional availability are key factors in its adoption. Training in Active Support is being offered to residential services staff by specialised services, usually upon request of the residential services themselves. The availability of Active Support training within a specialised service appears to depend largely on the background and experience of the people who are in charge of the service. The latest Active Support manual (Mansell et al., 2005) attempts to address this by widening the availability of Active Support training, since it is structured in a way that individuals can train themselves. This has the potential to increase adoption and implementation of

the model, even outside the context of residential services, in schools and families. The limited adoption of Active Support is in direct contrast to the impact of PCP on British policy which put forward person-centred planning approaches as the main strategy for supporting people with an intellectual disability through its influential White Paper 'Valuing People' (Department of Health, 2001). Despite their separate parallel development these two approaches could be combined to provide better services (Sanderson, Jones & Brown, 2001, 2002), especially in terms of the quality of staff work (Mansell & Beadle-Brown, 2004).

The experience of adopting PCP in British services has raised concerns about the relationship between planning and real life, in particular when the goals proposed have resource implications (system and skill resources; Mansell & Beadle-Brown, 2004). Small-scale implementation of Active Support so far has shown that it can be a functional model, as it addresses directly staff skills by training staff to support people to achieve the goals that have been set, and thus avoiding being an 'activity trap' (O'Brien, 2004) or a 'displacement activity' (Mansell & Beadle-Brown, 2004) where staff invest time and effort into creating plans that realistically cannot be put into action because of constraints. However, if Active Support were to become a system-wide approach, it is not known how large a system would need to be for Active Support to avoid this problem. There is a great amount of planning and data generated by Active Support implementation and it has yet to be shown how large a service would need to be to cope with this amount of data. There is no research evidence so far to demonstrate the role of the monitoring system in the evaluation of effectiveness or the maintenance of the model. In our experience, only a few services so far have managed to achieve full-scale implementation of Active Support (i.e., implementation of all structural components), and one reason for this could be service restrictions related to monitoring

implementation. Service resource restrictions have been identified as one of the factors implicated in the non-successful implementation of behavioural programmes (Corrigan, Kwartarini, & Pramana, 1992), even though data-based evidence of effectiveness is potentially a crucial factor in the adoption of behavioural programmes (Backer, Liberman, & Kuehnel, 1986; Stolz, 1981). Long-term maintenance of Active Support within a service is likely to depend on some form of monitoring of individual progress and service input, and the question that future research needs to address is what form of monitoring is more effective for long-term use by services. Data on individual participation coming from systematic use of recording forms, and more general evaluations of implementation from staff and management (Mansell et al., 2005) are both likely candidates. Although it is likely that effectiveness might be operationalised in different ways across different services, having a specified set of outcomes and specific procedures for measuring these is essential for evaluating programme success beyond the individual service.

Another dimension in Active Support research that is open to investigation has to do with sufficient and necessary conditions in terms of training for Active Support to be functionally present in a house. There is some evidence from previous research (Jones et al., 2001a) that staff training based only on workshops may not be as effective as training that includes both group workshops and individual Interactive Training. However, in the Jones et al. study the lack of effectiveness could also be attributed to the fact that the lead trainers were service managers and there was no involvement from researchers as in the other two groups. Therefore, the question about the differential impact of the two training components and whether they are both needed to make a difference still remains. If changes in staff behaviour are the output and changes in residents' behaviour are the outcome, the issue of 'quantity' of training is relevant to

both of them. From an applied perspective, it is important to establish whether an incomplete or partial implementation of Active Support can have an impact on people's quality of life or whether all elements of Active Support need to be functionally present for significant changes in the outcome. As an example, if Activity and Support Plans are being used in the house, this can make a difference in the experience of the daily living through increased participation. If, however, there are no Opportunity Plans, does this impose serious limitations on what residents could be doing and learning? So far, studies have not taken a long-term view of Active Support effects and they have not included learning as an outcome. While there is some evidence for improvements in adaptive skills (Mansell et al., 2002; Stancliffe et al., 2007), outcomes measured so far relate mainly to daily participation and staff assistance required to facilitate this participation.

The degree of programme implementation (or fidelity) is another dimension that is currently missing from evaluation research. Studies so far have not described the changes within the operational system of the house that happen after the introduction of Active Support and how they relate to observed changes in residents and staff. Future research needs to address this by measuring, for example, how implementation of Activity and Support Plans relates to an improvement of the current quality of life for the residents and how implementation of other system components (e.g., Teaching Plans) affects skill development of residents in the longer-term and informs daily activity planning. Both participation in activities and personal development are important dimensions of the quality of a person's life (Felce, 1997). Ensuring a better quality of life on a daily basis through participation in activities, without setting goals for the future, could result in daily routines becoming less purposeful and more repetitive over time and choice of activities being more of an incidental rather than a

meaningful exercise. While Active Support's main aim is to improve participation in activities – and research has demonstrated that it can do this – the question that research needs to address now is whether maintenance of these successful outcomes can be achieved in the absence of medium-term planning for skill development and learning.

All the factors identified above as potentially important in the maintenance of Active Support relate to service or model characteristics; service restrictions in terms of capacity; extent of monitoring used for progress evaluation; and the role of medium-term planning for each resident. Successful maintenance will also depend largely on staff factors, since staff are the main deliverers of this programme on a moment to moment basis. Staff beliefs about the effectiveness of the programme and the compatibility of the programme's principles with staff attitudes are important factors in the implementation of behavioural programmes (Ager & O'May, 2001; Corrigan et al., 1998; Hastings, 1997; Hastings & Remington, 1993). Active Support implementation requires changes in the organisational structure of the service in terms of team meetings and staff communication, so staff relationships and the role of managers might initially be more important in the implementation of the model than any resource restrictions.

A very important dimension for future research is the effect of Active Support on challenging behaviour. Outcomes have been inconsistent, with some studies reporting a significant decrease (Saxby et al., 1988), no significant changes (Jones et al., 2001a; Mansell et al., 2002; Stancliffe et al., 2007) or significant increases (Bradshaw et al., 2004). In these studies, challenging behaviours have been observed as five different topograghies: stereotypy, aggression, property damage, self-injury, and other inappropriate behaviour. However, reliable measurement of challenging behaviours is not always feasible; Mansell et al. (2001) suggest that 20 sec momentary time samples are not an appropriate indicator for low-frequency major challenging behaviours such as

aggression. There is a need for more studies that focus on challenging behaviour changes as a main outcome and where these behaviours can be reliably measured by direct observation and/or rating scales. The lack of follow-up information on challenging behaviour changes needs to be addressed with more longitudinal designs, as it is very likely that short-term changes in challenging behaviour can be different from any longer-term effects, given the persistence of challenging behaviours over time (Emerson et al., 2001b).

The relation between staff behaviour changes and any potential changes in challenging behaviour following Active Support training also requires further exploration. In Active Support staff are trained to increase behaviours that initiate and maintain engagement but do not directly intervene with challenging behaviours. However, there are indications that the presence of severe challenging behaviour interacts with adaptive skills and affects the amount of attention people receive from staff (Felce et al., 2003), which, in turn, affects directly activity engagement (Emerson, Hatton, Robertson, Henderson, & Cooper, 1999; Felce et al., 2002a; Perry & Felce, 2005). It has also been noted that staff behaviour can affect the development and maintenance of challenging behaviour, as its consequences are mediated by the behaviour of other people (Hastings & Brown, 2000; Hastings & Remington, 1994a). In addition, staff proactive behaviours, such as activity planning for every waking hour, create an environment where antecedent conditions that affect the motivation for exhibiting challenging behaviours (motivating operations) are expected to change. Therefore, staff behaviour can affect directly the occurrence of challenging behaviour or it can do this indirectly by changing the environment. Theoretically, Active Support proposes that the latter should happen. This hypothesis, however, has yet to be tested empirically.

In summary, Active Support, a model developed more than 25 years ago, based on the principles of Normalisation and using techniques derived from Applied Behaviour Analysis, has the potential to improve the quality of life for people with an intellectual disability who live in community settings, by increasing their opportunities to participate in activities of their daily lives, and improving the support they receive from staff. The studies described in this review were very important in establishing the effectiveness of Active Support, and they also have opened up a number of interesting dimensions that require further exploration in relation to the model's adoption by services and policymakers, the factors that affect its implementation in real-world settings, and the factors that will impact on its long-term maintenance.

Chapter 4: The Effect of Active Support Interactive Training on the Daily Lives of Adults with an Intellectual Disability.

Abstract

Interactive Training is one of the two staff training components of the Active Support model. The present study explores how effective Interactive Training is when offered to staff separately from the Active Support workshops, the other training component. We explored the effects of Interactive Training on resident activity engagement, challenging behaviours and staff assistance. Twenty-one adults with an intellectual disability (ID) living in residential settings participated. Observations and ratings of staff and resident behaviours were obtained before, immediately after the training sessions, and at six months follow up. Group-level analyses indicated a short-lived improvement in quality of staff support but, in general, there was an overall lack of change in staff behaviours, resident engagement and –observed and rated– challenging behaviours. However, subgroup analyses indicated that there was a significant improvement in engagement immediately after training for a distinct subgroup of participants; these had significantly higher aggressive behaviour ratings at the beginning of the study. Findings support the combination of the training components of Active Support for improvements in the quality of life for people with ID. Interactive Training may be worthy of future study as a stand-alone intervention for people with the most difficult challenging behaviours.

Introduction

Active Support is a multi-component person-focused model that aims to improve the quality of life of people with an intellectual disability (ID) by increasing the opportunities to participate in all types of activities of the daily life with the appropriate support from staff (Felce, Jones, & Lowe, 2002; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; see Chapter 3). Active Support was originally developed over 25 years ago as a response to the need for an operational framework in newly established community houses in the UK (Felce, 1989; Felce & Toogood, 1988; Jenkins, Felce, Mansell, de Kock, & Toogood, 1987). The model endorsed the principles of Normalisation as they were adapted in the British context (Ordinary living; King's Fund Centre, 1980), and included methods derived from applied behaviour analysis to achieve its goals. These goals include community participation, interpersonal relationships, skill development, choice and control, status and respect, and being treated as an individual (Chapter 3).

The implementation of the Active Support model has been shown to increase residents' engagement in daily activities (e.g., domestic or leisure activities) and the support they receive from staff (Bradshaw et al., 2004; Felce, 1989; Jones et al., 1999; Jones et al., 2001a, b; Mansell, McGill, & Emerson., 2001; Mansell et al., 2002; Stancliffe, Harman, Toogood, & McVilly, 2007). Improvements in resident engagement have generally been shown to relate to improvements in staff support (Jones et al., 1999; Jones et al., 2001a, b; Stancliffe et al., 2007; but not in Bradshaw et al., 2004). Staff support becomes more effective in eliciting resident activity engagement (Felce et al., 2000) especially when in the form of staff nonverbal assistance (Smith, Felce, Jones & Lowe, 2002).

Active Support evaluation studies have also examined its effects on residents' adaptive skills and challenging behaviours. There is some preliminary evidence of improvements in residents' adaptive skills (Mansell et al., 2002; Stancliffe et al., 2007). However, the effect on challenging behaviour is less clear. Researchers have reported no obvious changes (Jones et al., 2001a; Stancliffe et al., 2007), non-significant decreases (Saxby, Felce, Harman, & Repp, 1988; Mansell et al., 2001), or significant increases (Bradshaw et al., 2004) putatively as a result of Active Support intervention. Although the lack of consistency in the findings could be attributed to design and methodological differences among the studies, an added complication is the low frequency of most forms of challenging behaviour in adults with ID that does not allow for reliable observation and analysis (Mansell et al., 2001).

Training offered to staff of community group homes to implement the Active Support model consists of group workshops closely followed by Interactive Training. This training format has been used in most evaluation studies (Bradshaw et al., 2004; Jones et al., 1999; Mansell et al., 2002; Stancliffe et al., 2007) with the exception of Jones et al. (2001a). In the Jones et al. 2001a study, full training was provided to two groups of participants, but the third group was exposed to the group workshops only. These were delivered by service managers without any researcher involvement. The researchers found no significant changes in either resident activity participation or staff support in this third group (Jones et al., 2001a), which suggests that the lack of researcher (i.e., expert trainer) involvement, or lack of Interactive Training, or a combination of both conditions, might be an important factor(s) in bringing about the beneficial changes observed in the other two groups and in other evaluation studies.

In the present study, we evaluated the effectiveness of the second part of Active Support training, the Interactive Training, in improving the daily lives of adults with ID.

By examining the effectiveness of Interactive Training for Active Support as a stand-alone intervention, the differential impact of each training component might be clarified and insight gained on the necessary and sufficient conditions for staff training on Active Support (Chapter 3). In the present study, Interactive Training was provided in a service context without researcher involvement, where workshop training on Active Support had been delivered approximately 13 months before the Interactive Training. Conducting research in a clinical service that had followed this pattern of training involved a compromise on the possibility of conducting a full component analysis, but at the same time increased the ecological validity of potential findings. This was a 'real-world' application of a behavioural intervention which so far had been mainly used for research. It is often noted that moving from a research setting to real-world settings, behavioural programmes do not always result in the same outcomes (Emerson & Emerson, 1987; Hastings, 1997; Hastings & Remington, 1993).

It has been proposed that Active Support has the potential to act as preventative intervention for challenging behaviours, through changes in the social context of the residential environment (Chapter 3). Active Support puts in place a 'helpful environment' (McGill & Toogood, 1994) in at least three respects. First, there is increased staff support and assistance (Jones et al., 1999, Jones et al., 2001a, b; Stancliffe et al., 2007), suggesting that residents would not be expected to experience long periods of isolation. Second, staff behaviours are more likely to lead to engagement in appropriate behaviours (Felce et al., 2000; Smith et al., 2002), indicating that staff behaviours are better matched to the needs and abilities of residents. Third, increases in activities of the daily life (e.g., Jones et al., 2001b; Stancliffe et al., 2007) should provide increased stimulation. Finally, increases in residents' adaptive skills (Mansell et al., 2002; Stancliffe et al., 2007) may facilitate independence and

communication. Both low independence and poor communication skills may be risk factors for challenging behaviours (Borthwick-Duffy, 1994; Emerson et al., 2001a; Holden & Gitlesen, 2006; Lowe et al., 2007; McClintock, Hall, & Oliver, 2003).

In the present study, we explored the effects of Interactive Training for Active Support on challenging behaviour. Of the two training components required for the model's implementation, workshops and Interactive Training, it is the latter that might be expected to have the largest impact on challenging behaviours. Experimental manipulations (Iwata et al., 1994) have demonstrated how challenging behaviours are maintained by their consequences but, also, how the presence of certain environmental events or stimuli (antecedents) can evoke challenging behaviours maintained by certain consequences. Antecedent variables which affect the motivation for exhibiting challenging behaviours have been called establishing operations (Michael, 1993) or motivating operations (Laraway, Snycerski, Michael, & Polling, 2003). McGill (1999) and Smith and Iwata (1997) reviewed studies demonstrating the effect of motivating operations on challenging behaviour. Most motivating operations are directly related to staff behaviour (e.g., deprivation of attention, deprivation of contact, high-frequency instructions, complicated demands), whereas some others are more indirectly related (deprivation of tangibles, and lack of stimulation).

Interactive Training explicitly focuses on the behaviour of each staff member, and how this can be modified to increase resident engagement in activities (Toogood, in press). Staff are taught how to prepare their materials so that residents do not experience 'false' starts; how to use activity materials to communicate messages; how to arrange minimum environmental distraction; how to manage the rewards available; how to differentiate levels of support according to levels of need; and how to communicate commitment through their behaviour. In contrast, the main function of Active Support

workshops is to introduce the model's structural components to be used in each house and familiarise staff with their use. The workshops address the house's organisational system and activity scheduling for each resident, using mainly instruction methods. Interactive Training addresses individual staff behaviour using behaviour modification methods (e.g., prompting, demonstrating, fading, differential reinforcement; Toogood, in press). Thus, Interactive Training might be expected to modify several motivating operations for challenging behaviours, especially those directly associated with staff behaviour.

If Interactive Training has the potential to act as a proactive intervention for challenging behaviours, then this short intervention would be a cost-effective way of addressing problem behaviours at the level of the home environment. A decrease of challenging behaviours would be expected to have a positive effect on staff behaviour (Allen, 1999; Hall & Oliver, 1992; Hastings & Remington, 1994b; Oliver, 1995) and staff psychological well being, through their emotional reactions to these behaviours (Hastings, 1995; 2002b; Mitchell & Hastings, 2001; Mossman, Hastings, & Brown, 2002, Rose, Horne, Rose, & Hastings, 2004; Wanless & Jahoda, 2002). In addition, reductions in challenging behaviour may reduce the use of distressing physical management techniques (Hawkins, Allen, & Jenkins, 2005). Thus, reductions in challenging behaviour are an important service outcome.

In summary, the aim of the present study was to explore the effect of Interactive Training for Active Support on staff assistance and resident activity participation. We were also interested in the potential of Interactive Training to affect challenging behaviours. We predicted that these behaviours would decrease as a result of Interactive Training and through related changes in staff assistance.

Materials and Methods

Participants and Settings

Twenty one adults with ID living in community homes participated in the study. Their average age at the beginning of the study was 46.5 years (range 28 to 75 years). There were 12 men (57%) and 9 women. According to the information made available by service managers, 15 (71%) participants were classified in the severe ID range and the remaining nine had moderate ID. Four participants (19%) had a diagnosis of autism, and nine (43%) had current epilepsy. Participants lived in 10 community houses either alone or sharing with other people (maximum number of residents per house was four). Participants were supported 24 hours a day by paid staff. During the course of the study, one participant was relocated from his community home to a medium secure unit due to serious challenging behaviour. Therefore, follow up data are available on 20 residents.

In this service, a variable implementation of the structural components of Active Support was indicated by the Active Support Checklist (see Measures below). For the majority of participants (81%) there was some evidence that they had daily activity schedules, activity protocols and opportunity plans, and some data collection on activity participation was taking place for 76% of them. However, support plans for allocating staff time were reported for only about half of the participants (48%), 33% were reported to have communication guidelines in place, and teaching plans (i.e. plans for formal teaching of new skills) were present in only 19% of the sample.

Residents were supported by a total of 58 staff who, subsequently, received Interactive Training for Active Support (full sample description in Chapter 5). Staff were on average 44.5 years-old (range 26 to 65 years) and 53% of them were women. They had been working in this service for an average of six years (range one to 19 years). Eighty per cent were working full-time (37.5+ hours per week). Forty one per

cent had participated in Active Support workshops provided by the service approximately one year before Interactive Training sessions. Thirty nine per cent of staff had also completed a two-day training course on physical and non-physical management of challenging behaviour (accredited by the British Institute of Learning Disabilities) in the 12 months preceding Interacting Training.

Measures

Resident characteristics. The participants' level of adaptive functioning was measured using Part One of the Adaptive Behavior Scale-Residential and Community version (ABS-RC:2; Nihira, Leland, & Lambert, 1993). This scale measures independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, prevocational/vocational activity, self-direction, responsibility, and socialisation. The scale provides three factors: personal self-sufficiency, community self-sufficiency and personal-social responsibility. Nihira et al. (1993) provide information on content, criterion, and construct validity along with internal consistency (Cronbach's α range .82 to .99), test-retest reliability (*r* range .88 to .99) and inter-rater agreement (*r* range .83 to .99), which suggest that ABS-RC:2 Part One has excellent psychometric characteristics.

Information on residents' challenging behaviours was collected using the Behavior Problems Inventory (BPI-01; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). The BPI is a 52-item respondent-based instrument that measures stereotyped, self-injurious and aggressive/destructive behaviours. Each item is rated in terms of its frequency on a scale of 0 (never) to 4 (hourly), and severity on a scale of 1 (slight) to 3 (severe). Information on the instrument's psychometric characteristics indicates very good reliability and validity (test-retest *r*: .76; inter-rater intra-class coefficients: .91 and

internal consistency α: .83; good criterion and convergent validity; Rojahn et al., 2001; Rojahn, Aman, Matson, & Mayville, 2003). Appendix 2 includes a copy of the BPI.

Service characteristics. The presence of the structural components of Active Support was assessed in each house using the Active Support (AS) Checklist, designed previously by the clinical service as an audit tool for the extent of Active Support implementation. The AS checklist assesses the presence of daily activity schedules, the use of communication guidelines, the presence of support protocols for presenting activities, the presence of opportunity and teaching plans, support plans for organising staff time and whether data for participation at home and in the community are recorded (Appendix 3). Items on the checklist are scored as present (1) or absent (0). To describe use of the Active Support components in the present study a total score of items present was generated (range 0-7).

Resident and staff observations. Interactions between staff and residents were observed using hand-held computers (Hewlett Packard iPAQ rx3715®) with software designed for real-time data capture (ObsWin; Martin, Oliver, & Hall, 2000). Observation sessions were three hours in length and there were two such sessions at three time points: before and after Active Support Interactive Training and at six months follow up. All observations were conducted between 16:00 and 19:00. This was selected as the time of day where all residents would be at home, and activity was expected to occur in preparation for dinner and other evening routines. Each participant was observed for 10 mins in rotation. During the course of an observation, if a participant visited non-communal areas, (i.e., bathroom or bedrooms), the observation was suspended until the participant became available again. The average number of 10 mins observations per resident at each time point was 14 (range 4-33).

The observation protocol has been used in other Active Support evaluation studies (e.g., Jones et al., 2001a, b). Observations of resident behaviours included engagement in social interactions with a member of staff, engagement in domestic, personal or other non-social activities (leisure or educational). These behaviours were coded continuously with one second as the smallest time unit. In addition, aggressive, self-injurious, destructive, stereotyped, and other inappropriate behaviours were coded. These were also duration variables. Challenging behaviours were mutually exclusive between them and, also, mutually exclusive from engagement codes, with the exception of stereotypy. In other words, if a resident exhibited stereotyped behaviours while engaged in an activity, these two types of behaviours were coded simultaneously. If he or she exhibited some other form of challenging behaviour while engaged in an activity, the code for engagement ceased and the appropriate challenging behaviour code was selected. Observational codes of resident behaviours were exhaustive. When residents were not engaged in any activity or challenging behaviour, no code was selected. The absence of all resident behaviour codes was used to calculate a resident disengagement variable. Observational codes of staff behaviours were limited to those behaviours focused on the participant under observation. Staff behaviours included verbal assistance (i.e., instruction), non-verbal assistance (i.e., prompting and demonstration), physical assistance (e.g., hand over hand guidance), praise, feeding, processing (e.g., dressing or washing the person) and all other type of interactions not related to residents' activity engagement, like discussing what was on television the night before. With the exception of praise, all these variables were coded as continuous. All observation codes and their descriptions are summarised in Appendix 4.

Quality of staff support was assessed using the Active Support Measure (ASM; Mansell & Elliott, 1996), an observational rating scale that includes 15 items rated on a

0-3 scale, with higher values indicating better quality of the support environment. Examples of items in this scale include choice of activities available, sufficiency of staff contact and type of assistance extended to residents. Appendix 5 includes all items of the ASM. The scale has been used in other Active Support evaluation studies and researchers have reported very good levels of inter-rater reliability and internal consistency (Mansell et al., 2002; Mansell, Beadle-Brown, Macdolnald, & Ashman, 2003). The ASM was completed once for each resident at the end of a 3-hr observation period at baseline, post-test and follow up. A total ASM score was calculated by summing the ratings on the 15 items; higher total scores indicate higher quality of staff support.

Observation Reliability

Reliability of the observations was assessed by having a second observer code concurrently and independently 27.5% of the observations (42.5 hours out of a total 154 hours). Inter-observer agreement was evaluated by comparing the agreement of the two raters on the presence of each variable allowing a 2-second window for any possible differences in the clocks of the hand-held computers (Emerson et al., 1996). Agreement was measured using Cohen's Kappa. Average Kappas for resident behaviours were .71 (range .40-.89) for social engagement, .80 (range .68-.96) for domestic, .90 (range .88-.93) for personal and .82 (range .51-.99) for other activity engagement. Average Kappas for composite measures of resident behaviours (see Data Reduction and Analysis) were .90 (range .79-.97) for non-social engagement, and .88 for total engagement (range .77-.95). Average Kappa for challenging behaviours was .71 (range .61-.79). Average Kappas for staff behaviours were .67 (range .46-.76) for verbal assistance, .70 (range .54-.84) for nonverbal assistance, .66 (range .46-.81) for physical assistance, and .72 (range .49-.84) for other interaction. Average Kappas for composite measures of staff

behaviour (see Data Reduction and Analysis) were .71 (range .54-.85) for total nonverbal assistance, .70 (range .54-.80) for total assistance, and .74 for total contact (range .58-.83).

Reliability of the ASM was also assessed. The internal consistency of this scale across all time points was on average (Cronbach's α) .88 (range .78 to .93). Inter-rater reliability was assessed by having two observers independently observe and score the scale for 10 participants (48% of sample) at baseline, eight post-training (38%) and 10 at follow up (50%). Correlation coefficients (*r*) indicated very good inter-rater agreement: mean *r* .94 (range .89 to .98).

Procedure

The present study was reviewed and approved by the Local Research Ethics Committee of the Health Services Organisation which managed the community placements of the participants. In addition, the study was reviewed and approved by the Research and Development Department of the Health Services Organisation. The study was hosted in two departments of the Health Services Organisation: the Behavioural Support Team and the Community Residential Service. The latter provides staff and manages the residential homes, while the former provides peripatetic support and training to the staff and clients of the Community Residential Service.

The procedure for obtaining informed consent for participation was adapted to safeguard the interests of participants, and ensure that they provided independent consent wherever possible. A multi-step procedure (see Appendix 6) was followed where each participant's capacity was evaluated separately on the basis of his/her ability to comprehend and retain information related to the decision; to use and weigh this information in the decision making process; and to communicate his/her decision. There were 28 people in community houses managed by the Community Residential Service,

six of whom (or their legal representatives) refused participation (27%) and 22 who consented. Two participants provided independent consent. Baseline data were collected on 22 people. At the time of the post-test, one participant was moved to an out-of-area placement and was removed from the study. Of the 21 people for whom data were obtained at baseline and post-test, 20 people were still available at the time of the follow up, six months later.

At baseline, researchers visited each house to conduct two sessions of 3hr observations (including scoring the ASM) and met with staff to complete the rating scales (ABS, BPI, AS Checklist). Approximately one month (38 days on average) after the end of the Active Support Interactive Training, researchers returned to the houses for two 3hr observations (including scoring the ASM). They also met with staff to complete the BPI. Six months after the end of the training researchers visited the houses for two 3hr observations (including scoring the ASM), and met with staff to complete the BPI (one house was visited after nine months rather than six, due to residents' health problems).

Intervention Procedure: Interactive Training for Active Support

Interactive Training is a procedure that aims to increase the repertoire of staff behaviours directed at facilitating resident engagement in activities (Toogood, in press). Interactive Training sessions took place in each resident's house and involved one member of staff, two trainers, and one or more house residents. Each session lasted approximately one and a half hours and was divided into three parts: pre-training observations, coaching, and post-training observations. During pre-training observations trainers observed while staff and residents shared an activity and they identified the strengths and weaknesses of their interaction. Trainers observed staff and residents' on-task engagement (all behaviours related to participation in a shared activity), resident

challenging behaviours, and specific staff behaviours aimed at facilitating resident participation (preparation and presentation of activity materials, verbal and non-verbal assistance, management and use of rewards for participation, and the general style of staff interactions). Following a brief session of structured feedback, strengths and weakness of the interaction were addressed during the coaching phase, using verbal and nonverbal instruction, modelling and demonstration. The content and procedure of coaching was adapted to the needs of the particular staff:resident dyad. Post-training observations were identical to pre-training observations and a review summarised the whole training experience. Fifty eight members of the Community Residential Service received Interactive Training provided by the Behavioural Support Team, as part of the service's development. A more detailed description of the Interactive Training procedure can be found in Toogood (in press) and Chapter 5.

Results

Data Reduction and Analysis

To reduce the number of observed staff:resident interaction variables, more meaningful composites were created similar to those used in previous evaluations of Active Support (Jones et al., 2001a and b; Smith et al., 2002). For residents these variables were: engagement in non-social activities, total engagement and challenging behaviour. The composite variables of staff behaviours were staff total contact, total nonverbal assistance, and total assistance. The definition of each composite variable is presented in Appendix 4.

Descriptive statistics were generated for each person at each time point. Distributions of scores were examined and depending on normality of distributions (and homogeneity of variances, in the case of subgroup analyses) parametric statistics or

their non-parametric equivalents were used. The overall effect of Active Support Interactive Training was evaluated by comparing resident and staff behaviours across the three time points using one-way repeated-measures Analysis of Variance (ANOVA) or its non-parametric equivalent (Friedman analysis of variance). Where significant effects over time were indicated, appropriate post-hoc tests were used to examine pairwise differences. Group-level analyses were followed by subgroup-level analyses (see below) where an independent-groups t test or its non-parametric equivalent (Mann Whitney) was used to examine differences between subgroups.

Apart from comparing measures pre- and post-training, changes in the relationship between resident and staff behaviours were also explored. Time-based lag sequential analyses were performed to examine the effectiveness of staff behaviours (total assistance, nonverbal assistance and verbal assistance) in eliciting resident activity engagement (total engagement) and in reducing the probability of resident challenging behaviour. The conditional probabilities of resident total engagement at the three time points of the study were calculated for each of the three types of staff behaviour. Yule's Q was used as an index of sequential association. Yule's Q is a transformation of the odds ratio and it ranges from – 1 to +1 (Bakeman, McArthur, & Quera, 1996). For comparison with previous evaluations of Active Support (Felce et al., 2000; Smith et al., 2002), continuously recorded behaviours were converted to 'episodic' variables (Emerson, Reeves, et al., 1996). Thus, instances of resident total engagement which lasted less than 5" were deleted and instances of engagement separated by 10" or less were joined; instances of staff behaviour that were separated by 10" or less were joined, but no restrictions were placed on minimum duration. Challenging behaviour was not recoded into an episodic variable, as it has been suggested that recoding variables with a short average duration into longer durations can produce distortions in the sequential

relationships (Berchtold & Sackett, 2007). Investigation of the effect of staff behaviours on the onset of resident engagement and challenging behaviour took into account the duration of each staff behaviour; this was considered the safest approach as the average duration of these behaviours is close to or higher than 5" (see Table 4.1) (Yoder & Tapp, 2004).

Group Analysis: Effects of Active Support Interactive Training

Table 4.1 includes scores on all variables measured at each time point. Few statistically significant changes were observed over time. Staff nonverbal assistance did change over time (Friedman $\chi^2 = 8.10$, p=.017). Pairwise comparisons showed that the follow up levels of nonverbal assistance were significantly higher than post-training levels (Wilcoxon Z= 2.37, p=.018), whereas the differences between baseline and post training, and baseline and follow up were not large enough to be statistically significant (Wilcoxon Z= 1.65 and .11, respectively, p>.05). In addition, quality of staff support, as assessed using the observational rating scale (ASM), differed significantly across time points ($F_{(2)} = 3.86$, p=.030). Quality of staff support was significantly higher post-training compared to both baseline and follow up ($t_{(20)} = 2.13$, p=.046, and $t_{(19)} = 2.84$, p=.011, respectively). Follow up ASM scores did not differ from baseline. There were no significant differences in any of the remaining variables, although there was a trend evident for total assistance that reflected the findings for nonverbal assistance.

Table 4.1. Resident and Staff Behaviours Before and After Active Support Interactive Training, and at Six Months Follow up

	Baseline (SD)	Post (SD)	Follow up (SD)	p value
Observed staff behaviours: mean percentage of time				
Total contact	16.09 (7.93)	13.60 (8.19)	19.00 (10.08)	.287
Nonverbal assistance	3.99 (3.26)	3.10 (3.22)	4.78 (5.29)	.017
Verbal assistance	5.84 (3.98)	4.56 (3.27)	7.13 (5.39)	.157
Total assistance	7.97(5.13)	6.06 (4.74)	9.08 (7.19)	.058
Quality of staff support : mean total score on ASM	23.55 (6.52)	26.20 (9.32)	22.35 (9.04)	.026
Observed resident behaviours: Mean percentage of time				
Total engagement	41.13 (23.81)	37.49 (22.96)	41.81 (22.74)	.474
Non-social engagement	33.72 (21.88)	29.67 (20.91)	35.66 (21.75)	.341
Social engagement	8.41 (10.18)	8.15 (8.55)	8.40 (8.08)	.661
Challenging behaviour	5.89 (7.43)	2.90 (3.51)	7.52 (12.29)	.278

	Baseline (SD)	Post (SD)	Follow up (SD)	p value
Ratings of resident behaviour: Mean total score				
BPI SIB frequency	6.32 (7.13)	4.32 (4.14)	5.95 (7.52)	.802
BPI SIB severity	4.81 (5.64)	3.29 (3.39)	4.89 (7.00)	.423
BPI Stereotypy frequency	12.84 (14.74)	11.11 (11.22)	13.79 (14.42)	.824
BPI Stereotypy severity	8.86 (11.00)	7.19 (7.05)	7.68 (9.39)	.747
BPI Aggressive/Destructive behaviour frequency	8.47 (11.38)	5.74 (7.01)	8.37 (10.98)	.597
BPI Aggressive/Destructive behaviour severity	7.00 (9.83)	6.00 (7.11)	7.58 (10.42)	.882

Sequential associations between staff and resident behaviours indicated that the effectiveness of staff total, verbal or nonverbal assistance did not change significantly following Interactive Training (Table 4.2). Under all three environmental conditions, resident engagement was positively associated with staff behaviours (as would be expected), but the strength of the sequential association did not change significantly after the intervention. The number of participants in this calculation varied depending on the presence of one of the two behaviours each time. For example, only 11 participants experienced engagement in the presence of staff non-verbal assistance at all three time points. This variability was even more pronounced in the case of challenging behaviour. Therefore, it was not possible to generate valid conditional probabilities for these behaviours.

Table 4.2. Changes in Effectiveness of Staff Behaviour: Mean Yule's Q for Resident Total Engagement Given Staff Total, Nonverbal, and Verbal Assistance

	n	Baseline (SD)	Post (SD)	Follow up (SD)	p value
Stall total assistance	18	.607 (.194)	.635 (.181)	.608 (.196)	.733
Staff nonverbal assistance	11	.554 (.264)	.587 (.301)	.519 (.349)	.692
Staff verbal assistance	18	.607 (.176)	.626 (.190)	.625 (.163)	.869

Subgroup Analyses: Differential Effects of Interactive Training for Active Support

Given the small number of changes over the course of the intervention and the general downward trend in observed behaviours from baseline to post-training, we examined in more detail the changes in total engagement for each participant. This suggested the presence of two distinct subgroups: between baseline and post-training, there were eight participants whose total engagement increased (positive change scores)

and 11 participants whose engagement decreased (negative change scores). Between baseline and follow up there were 12 participants with positive change scores and six participants with negative change scores. Using positive/negative change scores for total engagement, the sample was split into subgroups. Two participants were excluded from each time period as their change scores indicated engagement changes of less than 1%. To validate the subgroups, two Group (2) X Time (2) ANOVAs were conducted. Between baseline and post-training, there was a significant interaction between group and engagement ($F_{(1)}=27.00$, $p<.001$), indicating that participants with positive change scores had a lower mean engagement at baseline (41.46%) which increased post-training (53.17%). Between baseline and follow up, there was also a significant interaction between group and time ($F_{(1)}= 29.26$, $p<.001$), indicating that people with positive engagement changes over this period had a lower mean engagement at baseline (33.02%) which increased at follow up (42.46%).

To investigate why for some participants engagement increased and for others it did not, the subgroups described above were compared on all baseline measures. These data are reported in Tables 4.3 and 4.4. Between baseline and post-training (Table 4.3), participants who experienced an increase in engagement had significantly higher scores on the frequency and severity of aggressive/destructive behaviours, as measured by the BPI at baseline ($t_{(17)} = 3.10$, $p=.007$ for frequency, and $U=18.00$, $p=.033$ for severity). There were no differences in baseline adaptive skills or any other baseline measure. The same analyses for those with an increase in engagement between baseline and follow up suggested that, with the exception of gender, they did not differ significantly on baseline measures from those whose engagement decreased between baseline and follow up (Table 4.4).

Table 4.3. Comparison of Baseline Measures between Participants with Baseline-Post Intervention Positive Engagement Change Scores and Those with Negative Change Scores

	Positive change scores (n=8)	Negative change scores (n=11)	p value
Baseline measures			
Age in years	45.55 (8.15)	49.05 (16.75)	.556
Gender	50% male	64% male	.552
ID classification	54.5% severe	87.5% severe	.127
AS checklist	4.00 (2.61)	4.25 (1.91)	.657
ASM	22.25 (6.74)	25.27 (6.20)	.325
BPI SIB frequency	8.75 (8.65)	3.73 (4.63)	.119
BPI SIB severity	6.63 (7.52)	3.00 (3.49)	.395
BPI stereotypy frequency	19.50 (19.59)	11.00 (11.40)	.249
BPI stereotypy severity	12.13 (14.98)	5.73 (6.17)	.216
BPI aggressive/destructive behaviour frequency	16.50 (13.52)	3.09 (4.44)	.007
BPI aggressive/destructive behaviour severity	14.13 (12.63)	2.73 (3.90)	.033
Personal self-sufficiency	54.50 (17.94)	63.82 (15.20)	.238
Community self-sufficiency	41.38 (22.08)	56.45 (37.42)	.325
Personal-social responsibility	28.38 (11.45)	35.73 (18.99)	.309

Table 4.4. Comparison of Baseline Measures between Participants with Baseline-Follow up Positive Engagement Change Scores and Those with Negative Changes Scores

	Positive change scores (n=12)	Negative change scores (n=6)	p value
Baseline measures			
Age in years	47.55 (15.09)	49.72 (11.15)	.760
Gender	67% female	11% female	.046
ID classification	83% severe	67% severe	.423
AS checklist	4.67 (1.67)	2.50 (2.74)	.102
ASM pre	23.25 (5.96)	23.67 (7.94)	.902
BPI SIB frequency	6.50 (7.79)	5.50 (5.43)	.964
BPI SIB severity	5.17 (6.28)	4.33 (4.68)	.778
BPI stereotypy frequency	14.83 (18.50)	11.17 (8.23)	.653
BPI stereotypy severity	9.08 (13.20)	6.83 (6.56)	.892
BPI aggressive/destructive behaviour frequency	7.50 (11.19)	9.33 (8.80)	.735
BPI aggressive/destructive behaviour severity	8.83 (12.37)	10.83(9.70)	.494
Personal self-sufficiency	50.00 (21.72)	64.50 (12.87)	.154
Community self-sufficiency	41.08 (30.03)	43.17 (25.36)	.886
Personal-social responsibility	28.83 (17.02)	30.00 (12.65)	.884

Two comparisons were conducted to explore whether increases/decreases in engagement were related to staff behaviours: a between-subgroup comparison of staff total, verbal and nonverbal assistance, and a comparison of mean Yule's Q for engagement in the presence of each of these staff behaviours. The results indicated that there were no differences between subgroups in the amount of (any) staff assistance or its effectiveness at either time point (baseline-post and baseline-follow up). These findings indicated that changes in residents' engagement were not associated with the observed amount of staff behaviours or with their effectiveness in eliciting resident engagement.

Discussion

The present study explored the effects of Interactive Training for Active Support on residents' participation in daily activities and the support they received from staff. The effects of Interactive Training on residents' challenging behaviours were also explored. Findings suggested that, for the whole group of participants, there was a significant improvement in quality of staff assistance (ASM) after the Interactive Training but this did not maintain over time. Staff nonverbal assistance significantly increased at follow up only. There was no evidence to suggest that staff total assistance, nonverbal, and verbal assistance became more effective in eliciting resident engagement as a result of the training. Changes in the effectiveness of staff behaviours at preventing challenging behaviours could not be examined due to the small number of people who presented with challenging behaviour during these staff behaviours at all three time points.

The overall trend for all observed behaviours to decrease post-training was explored with subgroup analyses. These indicated that for a subgroup of participants (n=8), total engagement increased at post-intervention. This subgroup had significantly

more frequent and severe aggressive challenging behaviours. Another subgroup (n=12) with increased engagement between baseline and follow up was not found to differ from those whose engagement decreased in terms of challenging behaviour, adaptive skills or any other baseline characteristic. Increases in engagement in these subgroups were not associated with improvements in staff total, verbal or nonverbal assistance either in terms of amount of support, or its effectiveness in eliciting engagement.

The trend of results from the present study differs substantially from other Active Support evaluation studies. In previous research, significant improvements in resident total engagement and staff support were evident shortly after staff training (Bradshaw et al., 2004; Jones et al., 1999; Jones et al., 2001b; Mansell et al., 2002, Stancliffe et al., 2007). However, a direct comparison between the present findings and other evaluations would not be meaningful as these evaluations included full staff training (workshops and Interactive Training), whereas in the present study staff only received Interactive Training during the course of the research. In our study, only about 40% of the staff had been exposed to the Active Support workshops one year previously, and only a partial implementation of the structural components of Active Support was evident in each house.

In the only other study to evaluate partial training (Jones et al., 2001a) service managers delivered the Active Support workshops to staff, but not the Interactive Training. Similar to the present findings, Jones et al. (2001a) found no evidence of improvements in resident engagement or staff assistance. Evidence from the Jones et al. and the current studies suggests that both Active Support training components are required for any beneficial effects on the quality of life for people with ID to become evident.

In terms of the impact of Interactive Training on challenging behaviour, the lack of a group-level change in challenging behaviours suggests a lack of evidence to support that motivating operations for challenging behaviour were modified, at least at the group level over the time period studied here. There are two possible reasons for this. The first is that it was perhaps unrealistic to expect a 1.5-hr intervention to change a large number of unidentified motivating operations, when the most successful antecedent-based interventions involve experimental identification of the maintaining reinforcer at an individual level (Wilder & Carr, 1998). Although it could be argued that the lack of a functional description of challenging behaviours was a drawback of the present study, the potential of Interactive Training and Active Support to modify motivating operations for problem behaviours is important exactly because it could be applied to more than one person by using less resource-intensive methods. A second possibility is that it might take longer than six months for any effects from broad motivating operation manipulations to become evident, especially when specific forms of behaviour are not targeted. Challenging behaviours are highly persistent over the course of a person's life (Emerson et al., 2001b; Murphy, Beadle-Brown, Gould, Shah, & Holmes, 2005; see also Chapter 2), which suggests that their maintaining reinforcers must also be highly persistent, thus making the contingencies less susceptible to changes introduced by modification of antecedents. A modification of the motivating operations for a specific behaviour would be expected to reduce the frequency of that behaviour by altering the effectiveness of the reinforcer. If the relationship between behaviour and reinforcer exists over many years, then it might take consistent and systematic exposure to modifications of the motivating operation for the effectiveness of the reinforcer to be diminished.

Despite the lack of overall change in engagement and challenging behaviours, the most aggressive subgroup of residents experienced significant increases in activity engagement. If we assume that staff behaviour facilitated the engagement of this subgroup (although changes in staff behaviour were not large enough for this to be apparent), then two questions are raised: Why did staff chose to focus on people with the most severe aggressive/destructive behaviours and not on some other subgroup (e.g., the least able residents); and why did this effect failed to maintain in the long run? Each of these questions is discussed further below.

Challenging behaviours are aversive stimuli for staff (Hall & Oliver, 1992; Oliver, 1995), and, their severity is associated with more negative emotional reactions in staff (Hastings, Tombs, Monzani, & Boulton, 2003). Residents are more likely to get a written behavioural plan when staff are the targets of challenging behaviours (Emerson et al., 2000). Severe challenging behaviours which directly affect other people might be more likely to elicit a response from staff or the service as a whole. It could be suggested that following Interactive Training, staff turned towards those for whom behaviour change was considered a priority. In terms of the lack of maintenance of engagement increases among the subgroup with the most frequent and severe aggressive behaviours, two non-mutually exclusive reasons are put forward. Hastings and colleagues (Hastings & Remington, 1994b; Hastings, Remington, & Hall, 1995) have demonstrated that staff behaviour is shaped, partly, by direct contingencies (i.e., directly reinforced or punished) and, mainly, by formal and informal rules which exist in their working environment. Any changes in staff behaviours which led the most challenging group of people to engage more in activities were probably not adequately reinforced (by perceivable improvements in residents' behaviours) to maintain and, thus, facilitate maintenance of the associated resident behaviours. It has also been

demonstrated that a staff member's perception of challenging behaviour episodes is largely affected by informal staff culture and communication regarding these behaviours (Noone, Jones, & Hastings, 2003). Interactive Training is delivered on a one-to-one basis and, as such, it would not be expected to have an impact on formal or informal rules which collectively shape staff behaviour.

The practical implications emerging from the present study relate to the training format. In service settings, both Active Support training components are required for measurable changes in staff and residents. Data from the present study and the Jones et al. study (2001a) demonstrate the diminished effectiveness of each training component when offered in isolation. In addition, short-term improvements in quality of staff support suggest that the maintenance of improvements in staff behaviour could be facilitated by ongoing exposure to Interactive Training sessions. Interactive Training could be made available to staff on a more regular basis, while future research needs to explore in more detail how staff apply these training-related skills, perhaps with staff reports as one way of eliciting this information.

The lack of a comparison group was a drawback of the present study, and inclusion of a waiting list control group in future studies could elucidate group-level changes in staff and resident behaviours. In addition to investigating staff reports of changes in their own behaviour after Interactive Training, it is also important to explore staff views on the Interactive Training experience and on their experience of its implementation in their every day work. Staff views of behavioural interventions, such as the Interactive Training and the Active Support model, are very likely to affect uptake and ongoing implementation of behavioural programmes (Hastings, 1997; Remington & Hastings, 1993).

Chapter 5: Interactive Training for Active Support: Perspectives from Staff

A version of this chapter is currently in press at *Journal of Intellectual and Developmental Disability* as: Totsika, V., Toogood, S., Hastings, R.P., & Nash, S. Interactive Training for Active Support: Perspectives from Staff.

Abstract

In this study, we describe the experience of participating in Interactive Training for Active Support. Staff (n=58) working with adults with an intellectual disability (ID) received Interactive Training on providing effective assistance for participation in daily activities. Semi-structured interviews were conducted with staff (n=37) on their experience of Interactive Training, the way it affected their work, and their views on Active Support implementation. High levels of satisfaction with Interactive Training were reported. Most staff identified at least one skill learnt during Interactive Training that they still used eight months after the training. Staff had difficulties describing a consistent picture of Active Support implementation across the service; a number of barriers were identified, with lack of managerial support as the most significant. Interactive Training can directly affect staff behaviour and has the advantage of being positively perceived by staff. However, Interactive Training alone cannot ensure successful Active Support implementation, which is affected by a number of other factors, such as managerial support and input, residents' challenging behaviours and staffing levels.

Introduction

Active Support is a model of care for people with intellectual disabilities (ID) that promotes an ordinary lifestyle (King's Fund Centre, 1980) through participation in meaningful everyday activities. The aim of Active Support is to help residents of small community homes to participate as independently as possible in age-appropriate meaningful activities in their homes, and in the community (Mansell, Elliot, Beadle-Brown, & Macdonald, 2002). Active Support was developed in the early 1980s and over time a number of Active Support approaches have become available (Brown, Toogood, & Brown, 1987; Jones et al., 1996, Booklets 1-6; Mansell, Beadle-Brown, Ashman, & Ockenden, 2005). Each approach includes a slightly different system for service implementation of Active Support but, in general, Active Support is implemented using a paper-based system for ensuring opportunities for resident participation in activities and skill development (Chapter 3). Support staff are trained to implement Active Support by attending group workshops and receiving in-house Interactive Training. The general goal of Active Support training is to increase the opportunities and assistance extended to residents by staff (Jones et al., 1999). The group workshops introduce staff to Active Support and the structural elements that need to be established in the service setting. The purpose of the Interactive Training is to train staff to improve the quality of moment-to-moment interactions with service users (Toogood, in press).

To date, the effectiveness of the Active Support model has been evaluated through measurement of resident behaviours related to participation in activities and staff behaviours related to assistance (i.e., staff verbal and nonverbal behaviours that aim to facilitate the engagement of the resident in an activity), using real-time observations of people in their homes. A number of studies demonstrate that the

implementation of Active Support significantly increases residents' engagement in activities and the support they receive from staff (Bradshaw et al., 2004; Felce, 1989; Jones et al., 1999; Jones et al., 2001a, b; Mansell, McGill, & Emerson, 2001; Mansell et al., 2002; Stancliffe, Harman, Toogood, & McVilly, 2007). Active Support also seems to be successful in changing the key mechanism improving residents' engagement in activities. That is, staff supportive behaviours become more effective in eliciting resident engagement after Active Support training (Felce et al., 2000; Smith, Felce, Jones, & Lowe, 2002). A number of other resident outcomes have also been measured, such as changes in adaptive and challenging behaviours (e.g., Jones et al., 1999; Jones et al., 2001a and b; Mansell et al., 2002; Stancliffe et al., 2007). However, very little is known about the views of consumers of Active Support.

Staff Perspectives on Active Support Training and Programme Implementation

One group of Active Support consumers – residents themselves – have received some research attention. Jones et al. (2001a) explored resident views on Active Support through focus groups between the most able residents and their independent advocacy consultants, who were not involved in Active Support training, and suggested that residents had a very positive view of the model as it was implemented in their homes. The other main group of Active Support consumers are the staff involved in its implementation. Staff views on Active Support training and the implementation of the model have not been the subject of research. However, the views of staff within services are important in the delivery of behavioural interventions in at least two respects. First, what various stakeholders think about an intervention and the manner in which it is delivered adds a dimension of feedback about the intervention that has been called social validity (Foster & Mash, 1999; Wolf, 1978). Not only do interventions need to be shown to be effective in changing behaviour, but they need to achieve outcomes in an

acceptable manner. Second, staff beliefs about behavioural programmes are likely to be critical for the adoption and implementation of behavioural programmes and technologies (e.g., Corrigan et al., 1998; Emerson & Emerson, 1987; Hastings, 1997; Hastings & Remington, 1993).

In addition to their general views, staff perceptions about the implementation of Active Support might provide some useful information about factors that facilitate or impede the maintenance of the model within services. A limited number of studies have examined the longer term maintenance of the effects of Active Support on staff and resident behaviours (Saxby, Felce, Harman, & Repp, 1988; Jones et a., 1999; Stancliffe et al., 2007), and have shown that improvements in behaviour are generally well maintained. However, researchers have not previously addressed factors that affect maintenance of Active Support in community houses.

In the present study we aim to address the issue of staff views on Active Support training and implementation in two ways: we interviewed staff about (a) their experience of Interactive Training, which was the part of Active Support training provided by their service at the time of the study, and (b) their experience of implementing the Active Support model, which they had been using over the preceding two years. Data collection was built around the clinical work of two departments from the same Health Services Organisation, where Active Support implementation was a service-led initiative and involved both workshop training and Interactive Training at separate time points. In this service, staff received Interactive Training 13 months after they attended the workshops. This differs from other Active Support implementations, where Interactive Training typically follows immediately after group workshop training (Bradshaw et al., 2004; Jones et al., 1999; Jones et al., 2001a and b; Stancliffe et al., 2007). For the purposes of the present study, everyone involved in Interactive Training

was invited to be interviewed eight months after Interactive Training was completed and almost two years after the initial introduction of Active Support. This allowed the present study to describe: (a) staff experience of receiving Interactive Training, (b) their experiences of implementing the skills learnt from Interactive Training in everyday work in the community houses, (c) their views on what the Active Support model can achieve within services, and (d) their views on factors affecting the longer-term implementation of Active Support.

Method

Service Setting

Fifty-eight staff of a Community Residential Service received Interactive Training for Active Support that was provided by a specialist department (Behavioural Support Team). Both departments were part of the same Health Services Organisation that manages residential homes for people with ID. Staff worked in 10 community houses where 20 adults with ID were provided with accommodation and support. The provision of IT was part of service development and took place 13 months after the service had completed workshop training on Active Support.

The staff who participated in Interactive Training had a mean age of 44.5 years (range: 26-65 years). Women were 53% of the staff group. Staff had been working in the Community Residential Service for an average of six years (range: 1-19 years), and in the ID field for an average of approximately nine years (range: 2-30 years). Eighty per cent worked full-time (37.5 hours a week) and 74% worked in one house, with 12% moving between two houses and the remainder working across three or more houses. One third had no formal educational qualifications. Nine staff (18%) reported having received training in a formal professional qualification such as psychology, nursing, or

social care. Twenty-one staff (41%) who participated in Interactive Training had also participated in the Active Support workshops 13 months prior to the Interactive Training.

Participants

Semi-structured interviews were conducted with 37 of the 58 staff who did the Interactive Training (a 64% participation rate). Five staff were on annual leave during the duration of the study, 11 were unavailable due to change of job or long-term leave, and four staff refused to participate in the interviews. The digital interview file for one staff member was lost.

The 37 interviewed staff reported working in Community Residential Service for an average of 7.9 years (range 2-20 years). The proportion of women in the interviewed sample was larger than in the trained sample (65% women). In addition, the interviewed sample included fewer staff who had participated in the AS workshops that had taken place 13 months before the Interactive Training (32% of the interviewees). The anonymity of the demographic information form that staff completed after their training session and again during the interview prevented us from matching the demographic information given at the two time points (at the end of training and during interviews) at the individual level. However, the low level of refusal to participate in the interview study (4 out of 58 people) and the high proportion of unavailable trained staff (20%) suggest that any differences between the trained and interviewed sample are due to staff turnover and not other biases.

Review and approval of the study was provided by the Research and Development Department of the Health Services Organisation and the study was registered as an audit for the Behavioural Support Team. Informed consent was

obtained from each interviewee prior to the interview. Participation was anonymous and all information collected during the interviews was confidential and anonymous.

Measures

Data collection was carried out at two stages. At the end of the Interactive Training session all 58 trained staff were asked to complete a form with demographic information and a feedback questionnaire on their experience of the training. The satisfaction questionnaire was developed by the service to be used as an audit tool for Interactive Training and for this reason it was considered important to exclude any information that would relate to staff identity. Therefore, both forms were completed anonymously. This prevented us from matching information on the trained sample characteristics with their questionnaire ratings. The feedback questionnaire consists of 20 items scored on a 1-5 scale, with higher values indicating higher satisfaction with the training (see Table 5.1 for items). Cronbach's alpha was .86, indicating very good internal consistency. The demographic information form was returned by 51 staff (88% return rate) and the feedback questionnaire was returned by 53 staff (91.4% return rate).

Eight months after the end of Interactive Training, staff participated in semi-structured interviews which covered four main topics: (a) delivery of Interactive Training (IT), which included a general evaluation of the experience ("How do you think the IT went?"), the positive aspects of the training session (e.g., "What went well during your Interactive Training? Can you give some examples of things you felt were going well during your training?"), staff perceptions of the helpful and less helpful characteristics of IT (e.g., "What would you say are the factors that make this type of training difficult?"), and an evaluation of changes for the future (e.g., "If you were going to do IT again, can you name two or more things that you would change?"); (b) implementation of training (e.g., "Is there something that you do differently in your

everyday work as a result of the training?"); (c) rationale for Active Support (e.g., "What can Active Support offer to the residents?"); and (d) implementation of AS (e.g. "Can you identify some of the things from AS that are used in your projects[1]"). A copy of the interview schedule is included in Appendix 7.

Training Procedures

Training the trainers. Ten people were trained to deliver Interactive Training for Active Support from an expert trainer in four group workshops that took place two months before the beginning of the Interactive Training. Trainers' training was based mainly on participation in training simulations (role play) and verbal instruction. Following the training, six people from the Behavioural Support Team provided lead training to the 58 staff. Ten trainers assumed the role of support trainer, seven of whom came from the Behavioural Support Team. An invitation to participate in "Training the Trainers" had been extended to the eleven managers (eight house managers and three team managers) of the Community Residential Service, but was only taken up by five house managers. Only three of these managers completed the trainers' training and later assisted, as support trainers, in 15 out of the 58 training sessions with staff who were not directly managed by them.

Interactive Training for staff. This is a 3-step procedure that aims to help staff establish a repertoire of behaviours that facilitate resident engagement in activities (Toogood, in press). Interactive Training includes pre-training observations, a coaching phase, and post-training observations (Toogood, 2005b; Toogood, in press). All training sessions took place in the residential houses and each session lasted between one and a half and two hours. During the pre-training observations, the member of staff engaged in an activity with the resident(s), while the trainers took a number of observations. The

[1] Project is the term used in this service to refer to a community home

support trainer observed staff and resident on-task behaviours using 10 sec. momentary time sampling and resident challenging behaviours using 10 sec. partial intervals (observations lasted about 10 minutes). The definition of staff on-task engagement included all staff behaviours that related directly to supporting the focal resident with the ongoing activity. Resident on-task engagement included all behaviours that related to preparing for or participating in an activity. The definition of challenging behaviour for each particular resident was agreed with the staff members before the observation began. The lead trainer focused on four main areas of the staff-resident interaction: (1) activity preparation and presentation, (2) support and assistance provided during the activity, (3) rewards available to the resident during the activity, and (4) miscellaneous and other stylistic issues. The lead trainer's observations formed a narrative that provided the basis for the verbal feedback given to the member of staff immediately after the end of the first phase. The verbal feedback lasted a maximum of five minutes and trainers pointed out areas of good practice to the staff and areas where there could be improvements. Although the lead trainer was the main deliverer of the feedback, the areas targeted for improvement were discussed with the member of staff and both parties had to agree on three or four training goals that were perceived as the most important ones. When agreement had been achieved, training moved on to the coaching phase which started with the member of staff planning a series of activities that lasted about 60 minutes. During the activities, the trainers interacted with the member of staff to assist participation in the activities and to facilitate the practising of the points raised during the feedback. The trainers used a combination of verbal (commentary, prompting, correction, and probes) and non-verbal methods (demonstration, prompting and error correction, and experiential learning; Toogood, 2005a) to teach staff. At the end of the coaching phase, the trainers discussed the activities with the member of staff

and briefly gave feedback. The last phase of the Interactive Training involved an activity that the member of staff shared with the resident, while the trainers repeated the observations they had taken during the pre-training phase. The final feedback was an overview of the whole training experience and of the differences observed in staff and resident behaviours between the pre- and post-training phase.

Data Collection Procedure

Interactive Training across the 10 residential homes was conducted over a period of five months (September 2005-January 2006). At the end of their session, staff were asked to provide demographic information and to complete the feedback questionnaire. The semi-structured interviews were conducted eight months after the end of the Interactive Training (July-August 2006). This time gap between training and interviews was estimated as an appropriate amount of time, where any short-term effects of the training on perceptions and behaviour would have dissipated, and sufficiently long for any longer-term effects of Interactive Training to be evident. The interviews lasted on average 13.60 minutes per person (range 7 mins to 19 mins). They were recorded using a digital voice recorder (Sony™ ICD-MX20) and then transferred to a computer for transcription.

Interview Analysis and Reliability

Content analysis was used to identify the themes emerging from the answers to the interview questions. The procedure involved identifying categories from the raw data, and providing a description for each category and the associated raw data (Thomas, 2006). The approach adopted for category development was to exhaust the content of an interview answer using the coding scheme without repeating categories. Therefore, unless otherwise stated, categories are not mutually exclusive but they are

exhaustive of the raw data associated with that research question. A three-step procedure for establishing coding reliability was followed. In Step 1, two raters coded independently and in parallel 7% of the research questions including 25% of the associated raw data to check on the clarity of the categories, and create a combined coding scheme. In Step 2, the second rater independently coded all the research questions with 16% of the associated data. The extent of initial agreement was established, discrepancies were discussed, and the coding scheme was finalised. Finally, in Step 3 the second rater independently coded approximately 25% of the interviews that had not already been used as a part of the coding training procedure (n = 9 interviews). Overall inter-rater agreement was calculated at Step 3 as the ratio of agreements to agreements plus disagreements multiplied by 100 to yield an average agreement (R) of 79% (range: 59% - 100%).

Results

Satisfaction Questionnaire Ratings

Immediately after the end of the Interactive Training, staff completed a feedback questionnaire with 20 items scored on a 1 (strongly disagree) to 5 (strongly agree) scale. For 15 out of the 20 items of the satisfaction questionnaire a higher score indicates more satisfaction. The remaining five items of the questionnaire indicate higher satisfaction when given a lower score. Staff responses across all 20 items are summarised in Table 5.1. The majority of staff expressed a high level of satisfaction with their training experience. Immediately after the training, 83% of the staff reported having enjoyed the training experience. The items with the highest satisfaction ratings included understanding the feedback (94%), learning new approaches and techniques (91%), feeling more able to assist with client participation in activities (92%), and agreeing that

the training was well organised (94%). However, approximately half of the staff felt that the training would be more effective with trainers who knew the clients well (53%), that they did not like being observed (43%), and that they were not adequately prepared for the training (49%), in terms of adequate information available within their teams before Interactive Training took place.

Table 5.1. Questionnaire Data on Staff Satisfaction with Interactive Training

	n	% of staff who agree [1]		n	% of staff who disagree[2]
Items where higher scores indicate more satisfaction:			**Items where lower scores indicate higher satisfaction:**		
1. I enjoyed the training experience	52	83%	5. I felt the training was intrusive	51	75%
2. I feel more able to assist with client participation	52	92%	11.I would prefer to be trained by my manager	52	76%
3. The clients seemed to enjoy the experience	51	65%	12. I did not like being observed	52	57%
4. I did not mind being observed	52	61%	16. The training was disruptive for the clients	52	68%
6. There will be lasting benefits for the clients	52	89%	20. The training would be more effective with trainers who knew clients well	52	47%
7. I would like to do this training again	52	70%			
8. I would recommend this training to a colleague	52	85%			

	n	% of staff who agree
Items where higher scores indicate more satisfaction:		
9. I learned new approaches and techniques	52	91%
10. I understood the feedback I was given	52	94%
13. I found the training relevant and helpful	52	90%
14. The training seemed to be well organised	52	94%
15. I felt adequately prepared for the training	52	51%
17. I feel more effective after training	52	75%
18. My performance during observation was typical	52	76%
19. My performance during coaching was typical	52	78%

[1] Staff who gave a score of 4 and 5
[2] Staff who gave a score of 1 and 2

Semi-Structured Interviews: Interactive Training

Delivery of Interactive Training. Eighty nine per cent of the staff had a positive experience of Interactive Training, and only two staff suggested that it was a negative experience. The same pattern of results was found for the 12 staff who had attended the Active Support workshops: 10 rated the Interactive Training experience as positive, one as negative and one as unclear. Staff responses related to the delivery of Interactive Training are summarised in Tables 5.2 and 5.3. The most frequently reported positive aspect of Interactive Training was learning a new skill (Table 5.2). Other positive aspects included the increased awareness about support roles, the positive feedback staff experienced from residents' increased participation levels during the training, and the whole Interactive Training session. When asked to think in general of in-house training and the factors that facilitate or impede it, staff responses were quite varied. No attempt was made to re-group these into a smaller number of categories because we wanted to maintain the level of detail as it was reported by staff (see Table 5.3). Staff emphasised the real-life context in which the training takes place (real house, real people, real interactions) as facilitating Interactive Training. Helpful characteristics which were related closely to the Interactive Training procedure included: in-situ training (24%), one-to-one training (22%), 'on the job' observations (22%), and the flexibility to adapt the content and procedure of Interactive Training according to the circumstances (19%). Less specific helpful characteristics included the opportunity for feedback and practice (16%), being trained by an external trainer (16%), and having the whole staff team being trained by the same group of trainers (5%). Being observed was the most frequently reported negative aspect of Interactive Training (Table 5.3). The observations of staff during training seem to be identified as a 'necessary evil': while 38% reported that they felt awkward, 22% said that having somebody observe the way

they work was helpful. Approximately one third of the difficulties associated with Interactive Training related to residents' abilities and behaviour: difficult to engage, challenging behaviour, and ease of being distracted. Scheduling the training sessions around residents' other activities and staff availability were other reported difficulties with Interactive Training sessions.

Table 5.2. Positive Aspects of Interactive Training (IT)

Category label	Category description	Staff (n=37)
New skill	Learning a new skill about how to provide support	57% (21)
Increased awareness	A gain in insight about support roles in general; being more aware that staff are there to support people instead of doing things for them	22% (8)
The whole IT procedure	The whole procedure of IT was positive	19% (7)
Positive feedback from residents' participation levels	Staff report witnessing increased levels of activity participation from residents during IT	19% (7)
Positive feedback from trainers	Staff receive feedback from trainers which validates good practice	5% (2)
Nothing was good about IT		3% (1)

Table 5.3. Interactive Training (IT): Helpful Characteristics and Difficulties

Helpful Characteristics		Staff (n=37)
In situ training	The training takes place in residents' own homes and makes use of real activities and real interactions that are happening in real time	24% (9)
One to one training	Staff receive individualised training	22% (8)
Being observed 'on the job'	IT is an opportunity for staff to have somebody observe their work	22% (8)
Flexibility and individualisation	Training/feedback is tailored to particular strengths/needs, likes/dislikes of the resident; IT process and content adapt according to circumstances	19% (7)
Feedback and Practice	IT is an opportunity to get feedback and practise new skills related to actual work	16% (6)
External Trainer	Having a trainer who is not part of the staff group; who comes as an 'outsider' to provide 'objective' feedback and see the interactions with 'fresh eyes'	16% (6)
Transfer of skills	IT facilitates transfer of skills to everyday work and other staff	8% (3)
Consistency	The whole staff team receives training from the same trainers. All staff work in the same way as a result of receiving the same training from the same trainers	5% (2)

Difficulties		Staff (n=37)
Being observed	Trainers' observations cause staff to feel awkward and to behave differently to how they would on their own	38% (14)
Residents difficult to engage	Residents do not engage in an activity readily and staff have to try harder to keep them engaged	30% (11)
Scheduling of the training	Training sessions clash with residents' daily activities; difficulties in scheduling training because of staff and resident availability	22% (8)
Residents get distracted	Residents get distracted by the presence of unfamiliar trainers and their behaviour is different	16% (6)
Insufficient training	Staff did not learn anything new; IT did not last long enough to learn new skills; IT not combined with AS model in order to be useful; one IT session not enough	14% (5)
Limited space and distractions	Difficulties during IT because of the limited space in the house or the distracting presence of other staff and other residents	14% (5)
Residents' challenging behaviour	Residents exhibit challenging behaviour which disrupts ongoing activities or prevents them from starting; residents not involved in IT exhibit challenging behaviour which disrupts IT	11% (4)

Totsika, 2007		154
Difficulties		Staff (n=37)
Staff apprehension	Staff report feeling nervous before the training because they were not sure what was going to happen	8% (3)
Training style	The way trainers deliver their feedback or praise is not considered helpful by staff	5% (2)
Reluctance to change	It is difficult for staff to change their behaviour or their way of thinking	3% (1)
Nothing about IT is difficult	There are no difficulties when doing IT	5% (2)

Although staff were never directly asked whether they wanted more Active Support training, 27% of staff requested more training especially with a focus on Interactive Training. Staff suggestions for changes to Interactive Training in future are summarised in Table 5.4. A conservative approach was adopted in coding these data. A code of No Change was only applied when nothing was identified as an issue by the staff member. Approximately one half of the staff reported that Interactive Training should be left exactly as it is. Within the remaining 51% of staff who suggested some type of change, the most frequently reported was that training sessions should be organised to fit better around residents' other activities (22%). Other proposed changes included the length of a training session (although perspectives on this varied considerably – see Table 5.4) and the number of people present during training. Despite the fact that 'being observed' was perceived as a difficulty of Interactive Training (Tables 5.1 and 5.3), only 3% of staff suggested that there should be a change in the way observations are carried out (Table 5.4).

Table 5.4. Suggestions for Changes to Interactive Training (IT)

Category label	Category description	Staff (n=37)
No change	IT should remain exactly as it is	49% (18)
Scheduling	Training sessions should fit better around residents' schedule	22% (8)
Length of sessions	Training sessions should be shorter, longer/more in the same day, shorter/more in the same day	16% (6)
Minimise distractions	There should be less people in the house during training (other staff, other residents, fewer trainers)	16% (6)

Category label	Category description	Staff (n=37)
Better pre-training information	Staff should have more information about the IT before it actually takes place	5% (2)
More familiarity with residents	Trainers should be more familiar with residents before IT takes place	3% (1)
Change in observations	There should be a change in the way observations are done so that staff feel more relaxed	3% (1)

Impact of Interactive Training. The majority of staff (86.5%) identified at least one way in which Interactive Training changed the way they work (32 out of 37). Nineteen per cent (7 out of 37) reported that after Interactive Training they are more aware of their role in the house as support workers, the residents' skills, and participation levels. Moreover, 73% (27 out of 37) identified at least one new skill they use in their work. The skills described related directly to the content of the Interactive Training (see Table 5.5), with the exception perhaps of more activities (i.e., doing more activities with the residents than before the training), which may be a generalisation effect of the training.

Table 5.5. Staff Behavioural Changes that Resulted from Interactive Training

Category label	Category description	Staff (n=27)
Task preparation/ presentation	Staff report preparing more appropriately for a coming activity in terms of materials required and layout of the environment	33% (9)
Verbal communication	Staff report giving more clear verbal instructions when they want to direct residents to a task or that they phrase their instructions in a way that facilitates engagement and avoids challenging behaviours	22% (6)
Body positioning	Staff report adapting their body positioning while doing an activity in a way that facilitates engagement and avoids challenging behaviours	15% (4)
More tasks/ activities	Staff report that they organise their daily work in a way that creates more opportunities for residents to participate in more activities	15% (4)
Use of prompts	Staff report using more or fewer prompts according to the resident's level of need	11% (3)
Increased praise	Staff report increasing the amount of verbal praise they provide during an activity	11% (3)
Task re-introduction	Staff attempt to bring back the resident to an activity that has been interrupted	11% (3)

Semi-Structured Interviews: Views on Active Support Model Implementation

Rationale for adoption of Active Support. Staff perceptions of the aims of Active Support are described in Table 5.6. The most frequent response was that Active Support offers continuity in residents' daily lives through the development of a functional routine and consistency in the way staff provide support (i.e., all staff working in the same way). Although continuity refers to the experience of the residents and consistency refers to the way staff work, they are both closely related: staff reported that having a schedule for the residents' activities allows each resident to know what activity they are doing, when and with which member of staff. This also allows staff who work in the same house to know what they are doing with the residents at any given time of the day and how they are doing the activities. The promotion of residents' independence and the opportunity for staff training were the second most frequently cited aims of AS. The perception of staff training as an aim of Active Support does not relate to the goals of the model, although staff training is the means whereby Active Support achieves its goals in relation to people with ID. Staff perceptions of Active Support aims and objectives did not emphasise increased participation, as this was reported by 16% of staff only. Similarly, skill development and learning, improved interactions, and improved quality of life featured lower in staff perceptions of Active Support goals within a residential service.

Staff's perception of the model's aims would have been shaped either by direct participation in the Active Support workshops, Interactive Training and experience of using Active Support over time, or just by Interactive Training participation and work experience. Given that Interactive Training did not explicitly address the goals of Active Support but referred only to improved interactions and increased participation, direct experience of Active Support implementation and workshop participation seem to have

shaped staff perceptions of the model's aims. With the exception of community presence, none of the reported aims in Table 5.6 seems to be reported more frequently by staff who had attended the workshops, suggesting that staff perceptions of the Active Support model aims were most likely shaped by their direct experience of using the model with residents over a two-year period.

Table 5.6. Staff Perceptions of Active Support (AS) Aims and Objectives

Category label	Category description	Staff (n=37)	Workshop attendees[1]
Continuity/structure	Continuity in residents' daily lives through a functional routine that sets out activities	27% (10)	50% (5/10)
Consistency	Consistency in the way staff support the client; all staff work in the same way to provide support	27% (10)	40% (4/10)
Self-determination	Promotion of residents' independence; residents exercise more choice and control over their lives	22% (8)	25% (2/8)
Staff training	AS is an opportunity for the service to provide staff training; either an explicit statement that AS is staff training or a description of AS effects where the primary beneficiary is staff	22% (8)	38% (3/8)
Increased participation	Opportunities for residents to engage more in ordinary activities of their daily lives	16% (6)	33% (2/6)
Skill development and learning	Residents learn new skills and extend existing ones by practice	14% (5)	40% (2/5)
Improved interactions	Improvement in the residents/staff interactions; residents experiencing more/better help and support from staff	14% (5)	40% (2/5)

Category label	Category description	Staff (n=37)	Workshop attendees[1]
Improved quality of life	A general statement about improvement in residents' quality of daily living	14% (5)	0% (0/5)
Community presence	Residents having a presence in the community and making use of community facilities	8% (3)	67% (2/3)
Individualised care	Service provision that is tailored to the resident's strengths and needs	3% (1)	0%

[1] The percentage of staff who attended the workshops among these staff who reported the AS aim

Implementation of Active Support: Current use of Active Support Elements in the Service. The final section of the interview schedule attempted to identify elements of Active Support that were in use in the houses and elements that were not currently implemented (see Table 5.7). Early in the analysis it became evident that there was considerable variability in the way people referred to Active Support elements. To identify what was being used in the houses, we relied either on the name given to the element and/or a description of its function (e.g., Participation Index; "...we do tick charts and we know how much they're doing, and we got a weekly total..."). The six Jones et al. (1996) booklets were used as a guideline to the structural elements of Active Support that need to be present in a house. In addition, the terminology used to refer to the structural elements was derived from a list used as an audit tool by the Behavioural Support Team before and after the workshop training to measure degree of Active Support implementation. Table 5.7 presents the structural elements that were reported as in use by staff of the ten houses. The distinction between Weekly and Daily Activity Plans was made based on people's description of the activity plans. When interviewees did not differentiate between weekly and daily, these were coded simply as Activity Plans. The results suggested that the two Active Support elements most commonly used were the Daily Activity Plans and the Opportunity Plans. The final two columns of Table 5.7 include information coded from the interviews to reflect incomplete implementation of specific Active Support elements. When interviewees stated that the element in question was used either by some staff but not all, or for some of the residents but not all, or for parts of the day but not throughout, the element was subsequently coded as partially used. Therefore, although 70% of staff reported using Daily Activity Plans, 23% of them reported that these plans were only partially used in the house.

Table 5.7. Active Support Elements Reported as in Current Use in the Community Homes

AS elements	Staff (N=37)	Staff reporting partial use of the element [2]
Activity Plans[1]	13% (5)	20% (1/5)
Daily Activity Plans	70% (26)	23% (6/26)
Weekly Activity Plans	24% (9)	-
Support Plans for Staff	24% (9)	-
Support Protocols for activities	43% (16)	-
Opportunity Plans	65% (24)	29% (7/24)
Opportunity Plans used in the past but not now	14% (5)	-
Participation Index	57% (21)	10% (2/21)
Community Logs	8% (3)	33% (1/3)
Communication guidelines	3% (1)	-

[1] This item was coded as mutually exclusive from Daily and Weekly Activity Plans
[2] The percentage is based on the number of staff who reported using this item. For example, among the five staff who reported using Activity Plans, one of them (20%) said these are only partially used. The dashes indicate that no one within the sample reporting the element suggested that it was not fully used.

To establish a clearer picture of the use of Activity Plans in the houses, we combined the information from participants who only reported using Activity plans generally, with those reporting using daily and weekly plans, and those reporting using only daily or only weekly plans. Ninety five per cent of staff reported using some form of Activity Planning. This suggests that within this service activity planning is being

implemented but we cannot clearly establish that all the houses use Activity Plans on a daily basis.

The difficulty staff had identifying Active Support elements was more pronounced during the next part of the interview where they were asked to identify the elements of Active Support they did not use in the houses. People could not name things they were not aware of, and so they found it difficult to reply to the interview question. The prompts used by the interviewer in this section reflected the hierarchical nature of the Active Support components, with the Daily Activity Plans as the basis of the model and the Individual Plans at the higher end. Therefore, if a person reported using Daily Activity Plans, the prompt for what is not being used would be about Opportunity Plans. Accordingly, if a member of staff reported using the Activity Plans, the Participation Index and the Opportunity Plans, the prompt given would be for Teaching Plans. The prompt included the name and a description of the Teaching Plan. A prompt for Teaching Plans was given in 68% of interviews with staff. Nineteen of the 25 staff who were prompted did not know what a Teaching Plan was and only four staff said they knew what Teaching Plans were but did not use them. For the remaining two staff it was unclear whether they had heard of Teaching Plans but they were not using them in the houses. Among the 19 staff who said they did not know what a Teaching Plan was, four of them had actually taken part in the AS workshops, where Teaching Plans had been described. This indicates either that these four staff had an incomplete knowledge of the Active Support components after the workshops, or that they forgot these components due to lack of use in their daily work.

Although the interview schedule was never intended as a tick-chart of what people use in the houses, the information provided by staff is interesting not only because it allows us to estimate the degree of Active Support implementation but also as

an insight into how much staff agree on what they were using. When examining the agreement among staff who work in the same house on what they report using from the Active Support model, staff only agree about 10% of the time with their colleagues (7 agreements out of a possible 68).

In summary, we see that: (a) not all elements of Active Support are used to the same extent in the houses, with only three elements (Daily Activity Plans, Opportunity Plans and the Participation Index) reported as used by more than 50% of staff (there were also indications that these three elements are only partially used); (b) there was a lack of agreement between staff who work in the same house as to which Active Support elements they are using, and (c) about two years after the initial introduction of the Active Support model none of the houses has progressed to implement the hierarchically higher components, such as Teaching Plans, which the majority of staff were unfamiliar with at the time of interview.

Implementation of Active Support: Barriers to Implementation. Staff were asked to identify barriers to implementation of the Active Support model as they had experienced it so far (see Table 5.8). The perceived barriers relate both to their experience of implementation, and to their assumptions about the lack of complete or appropriate model implementation. Nine staff did not identify any particular barriers to the implementation of Active Support. Barriers fell into three general groups: issues associated with the residents, staff-related issues, and service/management factors. The lack of managerial input on Active Support was the most frequently reported reason for incomplete implementation. Staff also identified residents' challenging behaviours as a serious obstacle to activity participation and suggested that the staff numbers in the house do not allow for more activities to take place. As it can be seen in Table 5.8, a large number of barriers were identified, each reported by a relatively small percentage

of staff. This indicates that there is no single significant barrier to long-term maintenance of Active Support, but a large number of perceived barriers with varying importance. The nature of the most frequently reported barriers indicates that the barriers do not relate to the nature and/or content of the programme but to more general issues in human service organisations.

Table 5.8. Barriers to the Implementation and Development of Active Support (AS)

Category Label	Category Description	Staff (n=37)
A. Resident Factors		
Challenging behaviour	Challenging behaviour gets in the way of activity participation or skill learning	19% (7)
Ability	Residents' ability prevents learning new skills or meaningfully applying AS components	14% (5)
Motivation	Residents do not want to participate in activities; their motivation is low	14% (5)
Serious health issues	Residents have serious health issues which prevent them from activity participation	8% (3)
B. Staff Factors		
AS plans are too detailed	Staff cannot cope with the amount of detail involved in AS plans; plans are not flexible enough to allow for unpredicted changes (e.g. staff absence)	14% (5)
Not enough time to do paperwork	Staff do not have enough time to do AS paperwork because they are otherwise engaged attending to residents' needs	8% (3)
AS plans take too long to draw up	Staff do not have the time to develop AS plans (Activity Plans, Opportunity Plans etc)	8% (3)

AS plans are not in good working order	The paper system that supports AS includes forms which are not clear because (a) staff forget to fill them in and leave blank spaces, (b) they are mixed up with other papers from the Care Plan, and (c) paperwork is not organised properly	8% (3)
No need for change	There is no need to change existing AS or for things in the house to change. Everything is fine as it is	8% (3)
Not enough time to do activities	Staff do not have enough time to do activities with the residents because they have to deal with other issues (health issues, personal care, cooking, cleaning)	5% (2)
C. Management and Service Factors		
Lack of management input	Managers do not update existing AS plans, they do not add new AS elements or they do not support staff to use existing AS plans; there is complete lack of manager or a discontinuity in management input due to manager changes	24% (9)
Not enough staff	There are not enough staff working in the house to do (more) activities with the residents	19% (7)
Team meetings	Team meetings do not happen as frequently as would be needed or do not happen at all; there is no time left in the team meetings to discuss AS issues; AS is not prioritised in team meetings	14% (5)

Discussion

The present study provides unique data on the experiences of staff participating in Interactive Training and their experience of implementing the Active Support model in a residential service. In terms of Interactive Training, at the end of their training, 83% of staff reported enjoying the training and 91% said they learned new approaches for supporting the residents. Eight months after the end of the training, 89% of the 37 staff who were interviewed reported that Interactive Training had been a positive experience for them, 57% identified learning a new skill as its most positive aspect, and 73% identified at least one new skill they used in their everyday work. What makes this type of training helpful is that it takes place in situ and involves one-to-one training paired with 'on the job' observations of staff work. These observations were also the aspect of the training staff found most difficult, along with resident factors that impeded their engagement in activities. Twenty two percent of staff also suggested that future training sessions should be scheduled to fit better around residents' other daily activities.

In relation to their experience of implementing the Active Support model over a period of two years, staff suggested that the main advantages of the model are the continuity in the residents' experience of daily living (where activities are mapped out throughout the day) and, also, the fact that Active Support introduces consistency in the way staff work, so that all members of staff work in the same way with a resident. Staff reports on the use of the Active Support components indicated a partial implementation of the model and a lack of agreement among staff working in the same house as to which components they were actually using. Staff perceptions of problems associated with maintaining Active Support related mainly to lack of managerial support and input, residents' challenging behaviours, and the lack of adequate staff numbers working in each house.

Social Validity of Interactive Training

Staff descriptions of their Interactive Training experience have implications for the social validity (Wolf, 1978) of the training. Behavioural interventions such as Active Support need to achieve measurable behaviour change in a manner that is acceptable to the consumers of these programmes. The development of a behavioural technology in the absence of consumer feedback on the acceptability of its processes might result in rejection of the intervention (Carr et al., 1999; Schwartz & Baer, 1991; Wolf, 1978) for reasons potentially unrelated to its effectiveness. Social validity is a multi-dimensional construct, measured on a continuum, with acceptability and importance as two of the main dimensions (Foster & Mash, 1999). The present findings support the social importance of the training goals of IT, along with the importance and acceptability of training procedures. The goal of Interactive Training is to teach staff skills which facilitate resident engagement (Toogood, in press), and learning a new skill was viewed as the most positive aspect of Interactive Training by more than half of the staff. In terms of the acceptability of the training procedure, more than 80% of staff expressed a high level of satisfaction with the training and half of them suggested leaving the Interactive Training procedure and content unchanged for future training. The significance of the effects of Interactive Training, the third dimension of social validity (Wolf, 1978), cannot be directly evaluated by this study. Although participants reported how Interactive Training changed the way they worked, they did not rate the importance of these new skills. However, one third of the participants voluntarily requested more training, suggesting that the effects of the training are valued and important to them.

Although establishing that Interactive Training is a socially valid intervention is an important aspect of Active Support evaluation, it is not sufficient to establish the

social validity of the whole Active Support model, or the effectiveness of Interactive Training alone in producing measurable behaviour change in staff and residents. For the latter, the self-reported behavioural changes need to be supported by more objective behaviour measurements, such as direct observations (see Chapter 4). The self-reported changes in staff behaviour in combination with the evidence of improved effectiveness of staff support in eliciting resident engagement in activities (Felce et al., 2000; Smith et al., 2002) suggest that better preparation and presentation of the coming activity, clearer staff verbal communication, better body positioning, better use of prompts, and increased praise might be important in improving the effectiveness of staff behaviours. An investigation of the social validity of whole Active Support model would need to address acceptability, both in relation to staff training procedures and in relation to model implementation as it is experienced by all relevant stakeholders (house residents, their families, friends or advocates, service staff and managers, the wider community).

Staff Views on Active Support Implementation and Barriers

Although all interviewees participated in Interactive Training, only 32% of them had actually participated in the Active Support workshops that the service had provided 13 months before the Interactive Training. This fact suggests a high turnover of staff within this service, which has implications for the way training should be offered to staff. In addition, interviewees' views on Active Support were largely based on their experience of using the model on a daily basis and not on their memory of the workshop training. Interestingly, results suggested that attendance at the workshop training did not affect staff perceptions of Active Support goals in a systematic way (see Table 5.6). In terms of barriers to the maintenance of the model, one third of staff focused on resident characteristics (ability, motivation, challenging behaviour, health problems), with challenging behaviour the second most frequently reported problem overall. This

finding is in contrast to data from other studies that report that personal characteristics of people with an ID are among the least reported barriers for implementing behavioural interventions (Hieneman & Dunlap, 2000; Johnson & Hastings, 2002). The other important group of barriers to implementation related to a lack of resources in terms of staff numbers and managerial support and input. Although, in the present study, 19% of staff suggested that staff shortages impede programme implementation, other studies found that this barrier is reported by as many as 50% of staff (Corrigan, Kwartarini, & Pramana, 1992; Emerson & Emerson, 1987). Research evidence has also questioned the basis of this perception that more staff might mean greater effectiveness of interventions. For example, in the case of AS, staff:client ratios have been found not to correlate with quality of staff support (Mansell, Beadle-Brown, Macdonald, & Ashman, 2003), as measured by an observational rating scale (Active Support Measure; Mansell & Elliott, 1996).

Staff suggested that the most important barrier to successful Active Support implementation and maintenance is the lack of managerial support and input, a factor that has been implicated in other behavioural intervention contexts (Corrigan et al., 1992; Emerson & Emerson, 1987; Hall & Baker, 1973). Evidence from case studies of Active Support implementation highlighted the need for greater managerial support, especially in cases of challenging behaviour (McGill & Mansell, 1995). In the present study, the lack of support to staff for implementing Active Support was compounded by the fact that the majority of staff expected to use the model had not received workshop training on it. New staff working in the houses would have to learn how to use Active Support based on informal information provided by their colleagues. The present data suggest that staff perceive the role of managers as important in leading the

implementation of Active Support but not as important in relation to the provision of training.

Study Limitations

A complete description of the experience of Active Support implementation would require information from other groups of people who are directly or indirectly involved, such as managers, house residents, and their families or advocates. Future research is needed to combine information from all stakeholders to provide a more comprehensive picture of each of these groups' experiences of Active Support. A further limitation of the present study is that the findings may not generalise to other services. The training experience and model implementation could be service-specific and not necessarily reflect the experience of staff in other services. However, the uptake of Active Support in UK services is limited (Chapter 3), and so the data from staff involved with this service-led initiative provide a unique insight into a 'real world' application of Active Support. Finally, it is important not to overinterpret the data from the present study which was not designed to be an evaluation of Active Support. The present study cannot provide definite answers regarding the optimum format of training and model development, but it can give us valuable descriptive information on factors which may be important for staff training on Active Support and model maintenance.

Implications for Training Delivery, Model Implementation and Research

A number of implications can be drawn from the present findings. First, greater managerial involvement in delivery of Interactive Training may be significant - as has been identified for other behavioural interventions (Gentry, Iceton, & Milne, 2001; Smith, Parker, Taubman, & Lovaas, 1992). Greater managerial involvement in parts of the training procedure, even if managers do not actually deliver the training themselves,

might facilitate understanding of the behavioural changes that staff need to make, and managerial support to achieve these changes. Second, management of training delivery probably needs to involve a team which includes trainers as well as managers and staff representatives, to reduce problems of scheduling training sessions at appropriate times and to strengthen team communication (cf. Corrigan, McCracken, & Blaser, 2003; Dunlap et al., 2000; Hastings & Remington, 1993; Hieneman & Dunlap, 2000). Third, the large turnover of staff in this service suggests the need to offer Active Support training on an ongoing basis. Ongoing training could ensure a more uniform knowledge base for service providers – thus counteracting the effects of staff turnover - and set the basis for successful implementation.

The fourth area for implications relates to input and support from managers for the daily implementation of Active Support. Managerial/supervisory feedback has been found to be important in maintaining staff behavioural changes over time, especially when combined with other approaches (Jahr, 1998; Lowe et al., 2007; Reid, Parsons, Lattimore, Towery, & Reade, 2005; Richman, Riordan, Reiss, Pyles, & Bailey, 1988; Woods & Cullen, 1988). In addition, staff managers are representatives of the service system. If managers place less emphasis on the implementation of Active Support, then staff might perceive this as a message that Active Support is not a priority for the service. The service's buy-in with a programme has been reported as one of the most crucial factors for successful implementation by various consumers of behavioural programmes (Heineman & Dunlap, 2000). A final practical implication is that successful maintenance of Active Support may also depend on actively addressing residents' challenging behaviours more effectively.

In terms of evaluating the implementation of Active Support, staff reports, as used in this study, are not an accurate or informative measure of degree of

implementation, since a substantial degree of disagreement was noted among staff and indications of partial implementation became evident. Future studies need to address this by developing a more robust measure of programme implementation and combining information from a large number of sources.

Conclusion

This study demonstrated that in-house Interactive Training is positively perceived by staff in residential services and highlighted the importance staff attribute to Interactive Training goals and procedures, and the acceptability of training procedures. Interactive Training has the potential to positively affect staff behaviours, although this remains to be established by more objective measures of staff behaviour (as used in Chapter 4). However, successful Interactive Training cannot ensure successful implementation of Active Support. Staff in the present study perceived the lack of managerial support to use and develop Active Support in each house as the most significant barrier to implementation. Implications for future applications of Interactive Training and Active Support include greater managerial involvement in the training procedure and more managerial support in the programme implementation; collaboration between staff with different roles in the organisation in the delivery of training; and provision of ongoing training opportunities to counteract the effects of staff turnover.

Chapter 6: Discussion

The present thesis investigated the chronicity of challenging behaviours in adults with an intellectual disability (ID), and evaluated the potential of Active Support, and Interactive Training in particular, in improving the life of adults with ID and challenging behaviours. In this section, I will draw together the findings from the empirical studies presented in the thesis, identify their limitations, and discuss implications for future research and clinical applications of the Active Support model.

Challenging Behaviours and Factors that Affect their Chronicity

Findings from the longitudinal investigation of severe challenging behaviours in adults with ID (Chapter 2) indicated that aggressive, stereotyped, and self-injurious behaviours were very likely to persist in the absence of effective interventions. Between half and 70% of the participants who exhibited these behaviours at serious levels in 1992 were still exhibiting them in 2003. The presence of one of these behaviours in an individual's repertoire placed him or her at increased risk of still exhibiting the behaviour 11 years later. The investigation of the characteristics of the subgroup of participants whose behaviours persisted over time did not reveal a systematic pattern of personal characteristics that could account for long-term maintenance of these behaviours. Participants with persistent self-injury and stereotypy had decreased daily living skills at the beginning of the study compared to participants without persistent challenging behaviours. Persistent self-injury was also associated with younger age, as were physical attacks, while persistent stereotypy was reported for participants with decreased sociability skills. Although there is some research evidence of low adaptive skills in individuals with persisting challenging behaviours (Chadwick, Kusel, Cuddy, & Taylor, 2004; Kiernan et al., 1997), the present longitudinal investigation suggested that other characteristics, such as gender, communication skills, mobility, sensory

impairment, and mental health status, were not associated with persistent serious levels of challenging behaviours.

The first main conclusion from these findings is that challenging behaviours are highly persistent in adults with ID. The second conclusion that can be drawn is that, despite the paucity of longitudinal investigations of challenging behaviours (McClintock, Hall, & Oliver, 2003), and their methodological heterogeneity, the available evidence does not implicate any prominent personal characteristics in the chronicity of challenging behaviours.

The measured persistence of challenging behaviours could indicate persistence of the underlying mechanisms that maintain them. Personal characteristics have not emerged as important risk factors longitudinally (Chapter 2; Emerson et al., 2001b), and research evidence so far suggests that personal characteristics, such as ability and skills, remain relatively stable during adulthood (Beadle-Brown, Murphy, & Wing, in press; Stancliffe, Hayden, Larson, & Lakin, 2002). The latter suggests that future research should investigate the role of environmental factors in the long-term maintenance of challenging behaviours. If the factors that maintain challenging behaviours are in the individuals' environment, any changes in environmental characteristics should lead to changes in the persistence of challenging behaviours. Longitudinal studies of changes in certain environmental characteristics -the living environment during deinstitutionalisation- indicated varied effects on challenging behaviours (decreases, increases, and stability). Researchers have attributed this variability to several confounding factors, such as the type of behavioural assessment (Hatton & Emerson, 1996), or changes in the availability of behavioural supports (before and after the 1990s; Kim, Larson, & Lakin, 2001). However, it has also been suggested that what we measure as impact of deinstitutionalisation on challenging behaviour might not reflect

real change (i.e., change directly related to change in housing characteristics), but it could be mediated by changes in staff behaviour (e.g., staff noticing and reporting more the frequency of challenging behaviours; Stancliffe et al., 2002). The latter suggests that environmental effects on behaviour could be mediated by the behaviour of other people.

Staff behaviour makes up the social environment of individuals with ID and challenging behaviours. Cross-sectional studies have implicated staff behaviour in the development and maintenance of challenging behaviours. Carers' reactions to challenging behaviours are frequently counter-habilitative and contribute to the development and maintenance of these behaviours through positive or negative reinforcement, thus making them more likely to re-occur (Hall & Oliver, 1992; Hastings, 1996; Hastings & Remington, 1994a; Oliver, 1995; Oliver, Hall, & Murphy, 2005; Watts, Reed, & Hastings, 1997). Challenging behaviours, in turn, affect carer behaviour and carers' psychological reactions, making a feedback loop between challenging behaviours and carer behavioural/emotional reactions very likely (Hastings, 2002b, 2005). Findings from these studies suggest that staff behaviours implicated in the short-term maintenance of challenging behaviours need to be studied longitudinally. Future research needs to examine the stability of counter-habilitative staff behaviours over time, and the extent to which they are longitudinally associated with persisting challenging behaviours. If staff counter-habilitative behaviours are stable over time, it would be expected that their longitudinal relationship with persisting challenging behaviours would be bidirectional.

The interaction between the social environment (i.e. staff behaviour) and the personal characteristics of people who present serious challenging behaviours is another possible focus for future studies on persisting behaviours. Recent research evidence alludes to the effects of such interactions. Tynan and Allen (2002) found that staff

carers' causal beliefs about challenging behaviour are affected by the severity of their clients' ID, with staff perceiving individuals with mild ID as being more able to control the causes of their aggressive behaviours and, consequently, more responsible for their behaviour. Even though staff's attributions of control have not been associated directly with the way staff in clinical settings actually react to these behaviours (Hastings, 2005), they have been associated with negative emotional reactions such as anger (e.g., Dagnan & Weston, 2006). The experience of such negative emotional reactions may lead staff to avoidance behaviours towards people with challenging behaviours, thus inadvertently reinforcing the behaviours (Allen, 1999), even though their attributions about challenging behaviours indicate that staff are aware of the different functions (i.e. causes) a behaviour can have (Noone, Jones, & Hastings, 2006). Although this is just one example of the way personal characteristics (e.g., severity of ID) might interact with other environmental processes (e.g., staff behaviour) to maintain challenging behaviours, it suggests that studies which will examine the longitudinal relationship between stable staff behaviours and stable challenging behaviours might need to investigate the moderating role of other factors, such as level of ID, staff attributions of control, and staff emotional reactions to challenging behaviours.

Active Support as a Broad Environmental Intervention

Given the persistence of challenging behaviours over time and the limited availability of individualised, effective behavioural interventions (Emerson et al., 2000; Kiernan & Qureshi, 1993; Robertson et al., 2005), services for adults with ID should explore the possibility of broad environmental interventions as a less resource-intensive way to address challenging behaviours proactively. The present thesis proposes that Active Support is a model that could be used by services to improve the quality of life

for people with ID, and also create a helpful environment (McGill & Toogood, 1994) where challenging behaviours are less susceptible to reinforcement (Chapter 3).

The Active Support model presents a number of characteristics that make it a well-suited intervention for current British service settings. Its effectiveness in improving the levels of activity participation of adults with ID along with the quality and level of staff support is well established (Bradshaw et al., 2004; Felce et al., 2000; Jones et al., 1999; Jones et al., 2001b; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Smith, Felce, Jones, & Lowe, 2002; Stancliffe, Harman, Toogood, & McVilly, 2007). The principles underpinning the model were similar to those that shaped British policy (King's Fund Centre, 1980) and there is a match, both conceptually and practically (Felce, Jones, & Lowe, 2002; Mansell & Beadle-Brown, 2004; Mansell, Beadle-Brown, Ashman, & Ockenden, 2005), between current policy (Person-Centred Planning in *Valuing People*; Department of Health, 2001) and the way the model can be applied in community residential homes. Implementation of the Active Support model with the subsequent improvements in the quality of staff support and residents' lives does not involve increases in service expenditure for additional staffing or resources, as only existing staff are trained, and daily implementation requires only a paper-based record system.

However, for the Active Support model to be adopted and maintained in real-world service settings, a number of additional factors warrant further research attention (see Chapter 3). Among those is the potential of the model to impact on residents' challenging behaviours, and staff views of the training and its implementation. These two factors were explored in the two other empirical studies in this thesis (Chapters 4 and 5, respectively).

Interactive Training for Active Support: Is it Effective?

The main focus of the studies in Chapters 4 and 5 were the effects of Interactive Training for Active Support. Interactive Training is one of the two training components (the other one being workshops) required before staff start implementing the model in the residential community homes. It targets specific staff behaviours, such as staff focus of attention, style and rate of verbal instruction, and manipulation of rewards (Toogood, in press). In the context of Interactive Training, these staff behaviours are important for affecting the levels of residents' activity engagement. However, recent advances in our understanding of challenging behaviours indicate that such staff behaviours are also associated with an increased probability of resident challenging behaviours (acting as motivating operations, McGill, 1999; Smith & Iwata, 1997). Therefore, if Interactive Training can change these staff behaviours which are directly related to improvements in activity participation, it might also indirectly impact on residents' challenging behaviours.

We evaluated the effectiveness of Interactive Training in reducing residents' challenging behaviours through changes in staff behaviours (i.e. changes in the social environment of the residents with challenging behaviours). At the same time, we examined the direct impact of the training on the levels of activity participation, and quality and level of staff assistance (Chapter 4). With the exception of a short-term improvement in the quality of staff support, Interactive Training did not result in improvements in resident activity engagement and challenging behaviours, or amount and quality of staff assistance. This finding was similar to the findings of the only other study to examine the effectiveness of one Active Support training component (Active Support workshops; Jones et al., 2001a). In service settings, when staff received only the workshops (Jones et al., 2001a) or only the Interactive Training (Chapter 4), there

was no robust evidence of beneficial effects on the quality of life of residents as a whole.

However, further investigation of the findings suggested that there was a distinct subgroup of residents, for whom activity engagement increased significantly immediately after Interactive Training. These were the residents who staff rated as having the most frequent and severe aggressive/destructive behaviours. Engagement improvements in this subgroup were not maintained in the six months following the training. A subgroup of residents whose activity engagement increased significantly between the beginning of the study and six months after the training was not in any way different from those whose overall engagement levels decreased over the same time period. The lack of maintenance of this positive effect was attributed to the limited maintenance of changes in the contingencies that maintain staff behaviours, and also to the training's lack of impact on the informal staff culture that affects individual staff behaviour towards residents with challenging behaviour (Chapter 4). Therefore, Interactive Training might be beneficial in the short-term for those residents who exhibit the most difficult challenging behaviours. The question is, how might these short term gains be maintained? This is addressed in the following section.

Even though observations of staff assistance behaviours did not reveal any changes following the training (Chapter 4), staff reported that their behaviour did change after Interactive Training (Chapter 5). We interviewed staff eight months after completion of the training and the majority of them (about 90%) said that it was a positive experience, and provided specific descriptions of behavioural changes they experienced after the training which were still evident after eight months (73% of trained staff). However, when asked about their perceptions of the Active Support model's aims and objectives, very few (n=6 out of 37) reported that increased activity

participation was a goal. This could perhaps explain the absence of an observable increase in the amount of time residents spent engaged in activities after the Interactive Training (Chapter 4). If the majority of staff did not view the Active Support model as a way to increase resident activity participation, and Interactive Training failed to re-emphasise this goal adequately, then staff behaviours did not change enough for substantial engagement increases to become evident in the whole group of participants (as suggested by the time sequential analyses; see Chapter 4). Staff suggested that challenging behaviours impede activity participation and, hence, implementation of Active Support (Chapter 5), yet engagement increases were evident in the most aggressive residents (Chapter 4). In this particular service, a partial implementation of the Active Support model seemed to fail to effectively address challenging behaviour problems, but following Interactive Training staff were able to focus -even in the short-term- on improving the engagement levels of the most difficult residents. If this effect could be maintained, Interactive Training could facilitate the implementation of the whole Active Support model, irrespective of each resident's history of challenging behaviour.

Methodological Issues and Limitations

One of the main limitations of the studies presented in Chapters 4 and 5 was the limited external validity of the findings due to the convenience sampling method used in these two studies. Collaboration within a clinical setting for the evaluation of the effects of Interactive Training compromised the possibility of conducting a full component analysis of the Active Support training components, and also the extent to which house residents were representative of the adult population with ID in community settings. However, the adoption of Active Support by UK services is limited and its extent unknown (Chapter 3). For this reason, the clinical work of this service provider offered

a unique opportunity to describe how applicable Active Support is in a real-world setting, and thus enhance the ecological validity of the findings. Most importantly, the real-world setting enabled us to describe staff experience of the Interactive Training and a two-year implementation of Active Support, providing, for the first time, valuable insight in staff's perceptions of the model and potential barriers to its implementation.

Whereas the internal validity of the evaluation outcomes would have been improved by inclusion of a control group, understanding the pattern of the evaluation findings was enhanced by staff reports of their experiences. Indeed, the combination of staff reports with direct observations was one of the methodological strengths of the study. Combining quantitative with qualitative approaches helps address the limitations of each individual approach (Glasgow & Emmons, 2007). This combination is increasingly being adopted in clinical research to achieve more comprehensive descriptions (O'Cathain, Murphy, & Nicholl, 2007).

In terms of assessing the effectiveness of the training on staff behaviour, these two methods suggested seemingly contradictory things: staff reported behavioural changes, but direct observations did not reveal any staff behavioural changes. Although the direct observations were methodologically more rigorous, the discrepancy in the findings between the two methods could be attributed to the fact that the research questions in each study were different (Moffatt, White, Mackintosh, & Howel, 2006). However, it could also be suggested that the observational protocol used in the evaluation was not sensitive enough to capture any behavioural changes in the way staff reported them as happening. This protocol has been used in other studies (Jones et al., 2001b; Smith et al., 2002) to evaluate the effects of Active Support following full staff training, and in this respect, might not be specific enough to changes in staff behaviour induced by Interactive Training only. Of course, we should not dismiss the possibility

that staff behavioural changes might be far more subtle than staff would be willing to admit in the context of an interview. In other words, staff might have exaggerated their reports of behavioural changes in the context of an interview they knew focused on their experience of Interactive Training. However, staff were aware that the information they provided during the interview would not be disclosed to their employer. In addition, staff who felt that they learned nothing new from the training procedure stated it very clearly (five out of 37 staff, Chapter 5). These three potential reasons for the apparent inconsistency between the observational data and the interview data suggest caution when attempting to integrate findings from the two methodologies.

In terms of assessing the training effects on resident behaviour, the findings from the staff reports served to elucidate the pattern of findings from the direct observations. Staff reported that they perceive residents' challenging behaviours as an obstacle to daily activity participation (Chapter 5), which in one way potentially supports their focus on residents with the most difficult challenging behaviours, immediately after the training (Chapter 4).

A further complication of the design of the study presented in Chapter 4 was the previous provision of Active Support workshop training. In this service, workshops were offered to staff 13 months before Interactive Training. Ideally, an evaluation of Interactive Training would have been conducted in a service where staff had no previous experience of the workshops. As this was not the case in the available service, the presence of the structural components of Active Support (Chapter 4), and the percentage of staff who had participated in the workshops (Chapters 4 and 5) were measured. Some Active Support structural components were expected to be present in each residential home, and the Active Support Checklist confirmed a partial implementation of the model's components (Chapter 4). More importantly, the

percentage of staff who attended the workshop training was the minority (40%) of the staff who received Interactive Training. The high level of staff turnover and the temporal distance between the two training events suggest that Interactive Training was effectively evaluated as a stand alone intervention.

The inclusion of a six-month follow up was considered a prerequisite for the evaluation of the effects on resident and staff behaviours, as the medium-term effectiveness of Active Support has not been explored to date (Chapter 3). Few Active Support evaluation studies have so far included follow up data (Jones et al., 1999; Saxby, Felce, Harman, & Repp, 1988; Stancliffe et al., 2007), and only one included follow up data on challenging behaviour (Saxby et al., 1988). In the Saxby study, two years after implementation of the model observations of inappropriate behaviours decreased from 14% to 4% in 10 residents, while levels of stereotyped behaviours remained stable (Saxby et al., 1988). In our study, levels of challenging behaviour did not change significantly from baseline to follow up six months later. Given the chronicity of challenging behaviours (Chapter 2; Emerson et al., 2001b), changes in their observed frequency might be slow, and a follow up longer than six months might be needed.

The observational data on residents' challenging behaviours limited our ability to directly address the research questions. The first problem was that there were not enough observations of specific types of challenging behaviour to reliably analyse them individually (cf. Mansell, McGill, & Emerson, 2001). Similar to other evaluations (Bradshaw et al., 2004; Jones et al., 2001b), stereotypy was the most frequently observed type of behaviour. Even after grouping them together (as challenging behaviour), there were not enough instances of challenging behaviour under each environmental condition (type of staff assistance) to produce reliable indices of

sequential association. In the following section, I will discuss possible ways to address this issue in future evaluation studies.

Implications for Future Research

The findings of the studies included in the present thesis point to three main directions for future research: extent of Active Support implementation, challenging behaviour, and environmental interventions. Each of these directions will be addressed in this section.

The first area for future research relates to the assessment of programme implementation. Evaluation studies so far have not examined the extent of Active Support implementation when evaluating its effects. While these studies have established the effectiveness of Active Support, investigation of its long-term effects in clinical settings would benefit from inclusion of this parameter (Chapter 3). The study in chapter 5 indicated that in a real-world setting where Active Support structural components were in use for a period of about two years, only a part of the components was used. The question that arises is how the degree of programme implementation relates to outcomes, and whether the whole model needs to be in place for beneficial outcomes to occur. Researchers need to develop a robust way of assessing Active Support implementation. Findings from the present thesis (Chapter 5), suggest that asking staff which components they use in their work is not a very reliable way of describing degree of implementation. Staff who worked in the same community home agreed on which components they were using only about 10% of the time on average (Chapter 5). While a scale of items present (as the Audit Checklist in Chapter 4) can be useful in assessing how many of the components are in use, implementation assessments need to go further; a number of staff suggested that some of the Active Support components were only partially used (Chapter 5).

On the issue of challenging behaviours, the present findings did not provide a conclusive argument regarding the usefulness of Interactive Training on decreasing challenging behaviours through environmental modifications. However, they suggested that: (a) exploring challenging behaviours over time is best done with a focus on the individual type of behaviour (Chapter 2), (b) the use of durational observational codes for capturing each type of challenging behaviour does not overcome the problem of low frequency and low interobserver agreement on each type of behaviour (cf. Mansell et al., 2001) (Chapter 4), and (c) that an average of about seven hours of observations per resident does not necessarily result in sufficient frequencies of challenging behaviours under different environmental conditions (Chapter 4).

The above indicate the need to further explore the potential of Interactive Training in decreasing challenging behaviours using a methodology that allows sufficient frequencies of challenging behaviour to be captured, so that the effects of Interactive Training can be explored separately for each different type of challenging behaviour. The distinction among types of challenging behaviour could be based on topography (as suggested in Chapter 2), but also on behavioural function (see Discussion Chapter 3). For sufficient frequencies of challenging behaviour episodes to be available for analysis, the design of data collection could be expanded to include different times of the day. In the present study, we conducted the observations between 16:00 and 19:00 because this is the time of day when all residents were expected to be at home and when afternoon routines would take place. This approach enabled comparison with other Active Support evaluations that conducted observations at this time (e.g., Jones et al., 1999; Felce et al., 2000; Jones et al., 2001a, b; Smith et al., 2002; Stancliffe et al., 2007). While it is likely that this is the best time to assess the effectiveness of Active Support in increasing activity engagement, challenging

behaviours – which are inversely related to activity engagement, and their relationship is mediated by adaptive ability (Felce, Lowe, & Jones, 2002a) – might not occur at an adequate rate during this time period. The observational design could be expanded to include different times of the day, and the analysis could be expanded to include more types of environmental circumstances (e.g., absence of staff assistance).

Findings from the present thesis also suggested that staff perceive challenging behaviours as an important barrier to programme implementation (Chapter 5), and that Interactive Training might help staff support those residents whose behaviour they perceive as more difficult (Chapter 4). Future studies need to investigate possible ways of maintaining this positive effect of Interactive Training. But before focusing on maintenance, studies need to identify changes in the social environment of these residents that are associated with the observed improvements in engagement levels. The design and analysis of the present study did not identify changes in staff behaviours related to this positive effect (Chapter 4). Future studies might need to employ a research design that will facilitate discrimination between different types of staff behaviours towards different groups of residents. This approach could indicate whether staff differentiate their behaviour according to certain types of residents. One way of achieving this would involve evaluating Interactive Training effects in two separate groups of residents: those with severe challenging behaviours and those without. Splitting the residents into two groups would need to happen in advance, and the variable used for this decision is likely to be of importance for the outcomes. Findings from the present thesis suggested that baseline observations of challenging behaviours, which were mainly stereotypies, did not discriminate the residents who made gains from those who did not, whereas staff ratings of frequency and severity did (Chapter 4). In our case the discriminating variable was the rating of aggressive behaviours. Real-time

observations would be less likely to capture these lower frequency behaviours which have a potentially higher environmental impact than stereotyped behaviours. Staff in our study did propose finding it difficult to assist in activity engagement those residents who had severe challenging behaviours, suggesting that exploring staff views of their client group might be a useful starting point for deciding what groups residents might fall into. Direct observations of staff behaviour in each group before and after training could indicate whether (a) staff behaviours differ depending on resident group, (b) training changes staff behaviour differently for each group of residents, and (c) which staff behaviours are more frequent or effective within the most challenging group of residents.

In addition to changes in staff behaviour, other non-behavioural changes need to be explored. A proportion of staff participating in the current study (19%; Chapter 5) suggested that following Interactive Training they experienced a change in their awareness of their role in the house, the residents' abilities and needs. These were staff who did not describe specific behavioural changes, but indicated changes at a level which direct observation of their work would probably fail to capture. For example, when asked whether Interactive Training changed the way she worked, one member of staff suggested:

> Um, yes, I think I question myself at certain times, you know, that I'm doing the right thing for the clients, and take a step back and look at the whole picture, you know, if the client I'm working with is, um, agitated for some reason I sort of step back and think, right, well, why is it? Does he not want to do the activity? You know, is there something...? I think that, that I do that a lot more.
>
> (Staff 21, Chapter 5)

Studies have suggested that even when staff have the skills to implement behavioural programmes, they might be less likely to implement them if they find their approaches incompatible with their values (Emerson & Emerson, 1987; Hastings,

1997). In Chapter 5 staff reported perceiving continuity in residents' daily experiences as a more important aim of the Active Support implementation than increases in activity participation, which is a central goal of the model. In relation to challenging behaviour, and how this incompatibility of values might affect Interactive Training implementation, staff's immediate intervention strategies with challenging behaviour episodes are motivated by their wish to distract from the behaviour, prevent harm, try to find the causes of behaviour and create a positive atmosphere (Hastings, 1996; Watts, Reed, & Hastings, 1997), which may be in conflict with the Interactive Training emphasis on continuing with the activity at hand and ignoring the challenging behaviour. If such a conflict is present, staff may be less likely to persist with an ongoing activity when a resident exhibits challenging behaviour. Measures of staff values and motivation would provide useful information on how likely staff are to implement Interactive Training in their everyday work, and whether exposure to Interactive Training produces any changes in values and motivation to intervene with challenging behaviours. These findings would need to be related to any findings of changes at the level of staff behaviour (as described above), to fully describe how Interactive Training impacts on staff.

After identifying staff variables related to improvements in engagement in those residents who are most difficult to work with, future studies need to explore how best to maintain these positive effects. If the variables responsible for this positive effect relate to observed changes in the skills of staff, studies need to investigate how skills-related changes could be maintained in the long-term. A number of studies have highlighted the importance of supervisory feedback for maintaining changes in staff behaviour (Harchik, Sherman, Sheldon, & Strouse, 1992: Parsons & Reid, 1995; Reid, Parsons, Lattimore, Towery, & Reade, 2005; Richman, Riordan, Reiss, Pyles, & Bailey, 1988).

Future studies could examine the role of service managers in providing feedback for behavioural changes related to Interactive Training, and the extent of their involvement in relation to maintenance of staff behaviours. Repeating the training until behavioural changes have been achieved has also been proposed as a way of improving maintenance of behavioural skills (Ricciardi, 2005). Future studies could compare the effectiveness of one Interactive Training session against more than one sessions in maintaining changes in staff behaviours.

Additionally, should future studies suggest that the positive effects in engagement levels of the most difficult residents are also related to changes in the motivation and attitudes of staff, research needs to examine ways of enhancing this effect. Interactive Training does not directly address issues of staff values and motivation to intervene with challenging behaviours, but its delivery could be combined with other approaches that facilitate such processes. One such intervention is training in mindfulness. Being mindful is having a clear, calm mind that is focused on the present in a non-judgemental way (Singh, Lancioni, Winton, Fisher, et al., 2006). Its application in the field of ID as a carer intervention has demonstrated significant effects in the lives of people with ID and challenging behaviour. Specifically, staff carers who received mindfulness training reduced significantly the number of interventions used for aggression episodes (Singh, Lancioni, Winton, Curtis, et al., 2006); adults with ID were significantly more happy after their staff carers had received mindfulness training (Singh et al., 2004); and parent carers' exposure to mindfulness was shown to lead to decreases in noncompliance, self-injury and aggression in children with autism (Singh, Lancioni, Winton, Fisher, et al., 2006). Although the mechanism through which mindfulness produces changes in people's behaviour is not yet clarified, Singh, Lancioni, Winton, Fisher, et al. (2006) highlight the role of unconditional acceptance,

which would entail not focusing on challenging behaviours or ways to replace them, a focus of the mind on the here and now, and transformational changes in the neurophysiology of the brain. Researchers suggest that behaviour change in mindfulness is achieved through a transformation of the view of oneself and others (Singh et al., 2004). It could be suggested that mindfulness' emphasis on the here and now – as attentional focus – involves a disruption of the contingencies that maintain carer behaviour.

Similar to Active Support, mindfulness achieves its effects without using planned antecedent and consequent manipulations. Future studies could compare how staff's motivation to intervene with challenging behaviours (reactive management) is affected by Interactive Training alone, and Interactive Training combined with mindfulness training. If their combination makes staff behaviour less susceptible to reinforcement by residents' challenging behaviours, staff would be less likely to react in the presence of a challenging behaviour when they are sharing an activity with a resident. The implication of this would be that activity participation would be promoted, and challenging behaviours would not be directly reinforced. Therefore, it is worthwhile exploring whether the combination of Interactive Training with mindfulness can facilitate the proactive role of Interactive Training in reducing challenging behaviours.

Implications for the Application of the Active Support Model in Services

In light of the methodological drawbacks discussed above, caution is warranted when examining the implications of this thesis' findings for applied settings. A number of practical difficulties (presented in Introduction) affected the methodological design of the present studies (especially chapter 4), thus rendering the possibility of drawing firm conclusions difficult. The following suggestions should be regarded as tentative. Findings on the effects of Interactive Training on the quality of life of people with ID

(Chapter 4), suggest that Interactive Training as a single training component does not lead to long-term improvements in quality of staff support and cannot improve the levels of activity participation across residential homes. Evidence of diminished effectiveness of single training components (Chapter 4; Jones et al., 2001a) suggests that services need to offer staff the Active Support training model that has an associated evidence-base (Bradshaw et al.; Felce et al., 2000; Jones, et al., 1999; Jones et al., 2001b; Smith et al., 2002; Stancliffe et al., 2007): both training components (workshops and Interactive Training), and in quick succession between them. Evidence of high staff turnover (Chapter 5), partial implementation (Chapter 5), and short-term effectiveness (Chapter 4) suggest that a one-off training opportunity on Active Support cannot sustain long-term programme implementation. Services might consider offering training on Active Support more regularly to allow new staff to familiarise with this way of work, and existing staff to review their practices and progress to more advanced issues.

Evidence of differential effectiveness of Interactive Training for specific subgroups of residents (Chapter 4) suggests that Interactive Training might be particularly useful to staff who work with residents with serious challenging behaviours. While this is only a preliminary finding which cannot affect the work of clinical services, if future studies replicate this positive effect, then services might consider making Interactive Training available as an additional stand-alone intervention to staff who support residents with more severe challenging behaviours. In the previous section several ways were suggested to explore this effect further and examine how it can be maintained. The findings of future studies could indicate to practitioners whether they would need to adjust the content or the format of Interactive Training sessions to the targeted group of residents.

Summary

In conclusion, the present thesis demonstrated the high levels of persisting challenging behaviours, and indicated the need to explore dimensions of the social environment of adults with ID as they impact on the maintenance of severe challenging behaviours. Active Support is a model that not only improves the quality of life of adults with ID, but also impacts on their social environment through improvements in staff behaviour. As such, it is a likely candidate to be used as an environmental intervention that can proactively affect challenging behaviours. Interactive Training for Active Support, the model's training component which directly deals with moment-to-moment staff behaviour, did not improve overall activity engagement or challenging behaviour levels, but had a short-term effect on quality of staff support and activity engagement in residents with the most severe aggressive behaviours. While the main practical implication of this is that Active Support implementation requires both training components to be successful, it also highlights the potential of Interactive Training to improve the experiences of people with the most difficult behaviours.

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Appendices

Appendix 1: Part I and II of the Individual Schedule of the Challenging Behaviour Survey (Alborz et al., 1994)(Chapter 2)

	(1-3) Hester Adrian Research Centre - Behaviour Problems Survey Information about Individuals	(4-5) Health Authority (code as opposite)		CARD 1
1.	Age (in years)	Years		(6-7)
2.	Sex	Male..... Female.....	1 2	(8)
3.	Marital status	Single..... Other (please specify).....	1 2	(9)
4.	Place of residence	Family home..... Foster family home..... SSD or NHS hostel..... Hospital Ward..... Independent..... Other.....	1 2 3 4 5 6	(10)
5.	Most recent IQ score (If not known, go on to question 6)			(11-12)
	Name of test			(13)
	Year in which test was administered	19		(14-15)
6.	Degree of mental handicap (Severe handicap is understood to mean an IQ of 50 or less)	Borderline..... Moderate..... Severe/Profound..... Not assessed/cannot say.....	1 2 3 4	(16)
	* HARC USE ONLY (73-75) (76-77) (78-79) (80) COLUMNS (73-80) ARE CODED AS ABOVE ON ALL 4 CARDS			

Totsika, 2007

7.	Legal status of person		
	Not applicable	0	(17)
	Informal	1	
	Detained through the courts on a hospital order	2	
	Detained for assessment or treatment	3	
	Child in Care	4	
8.	How long has the person been attending, or living in this setting? (in years, if less than one year, enter 1).		(18-19)
9.	Are any of the following conditions present?		
	Downs syndrome? No	0	(20)
	Yes	1	
	Don't know	2	
	Cerebral palsy? No	0	(21)
	Yes	1	
	Don't know	2	
	Autism? No	0	(22)
	Yes	1	
	Don't know	2	
	Other known syndrome? (Please specify) No	0	(23)
	Yes	1	
10.	Psychiatric disorder (only enter if such a diagnosis has been made by a psychiatrist, do not guess).		
	Don't know	0	(24)
	No psychiatric disorder	1	
	Depressive illness	2	
	Other affective disorder	3	
	Schizophrenia	4	
	Psychotic condition (unclassified)	5	
	Neurosis	6	
	Other (not included above or unknown psychiatric disorder)	7	
11.	Does the person suffer from fits?		
	No (no medication, no seizures)	1	(25)
	No (controlled by medication)	2	
	Occasional seizures (less often than monthly)	3	
	One or more major seizures per month	4	
	a) Has there been a definite diagnosis of Temporal Lobe Epilepsy		
	Yes, Definite	1	(26)
	Yes, Query	2	
	No	3	
	Don't know	4	

3

12. i) Vision (If glasses are worn, code vision with glasses)

Normal	1	(27)
Poor	2	
Blind	3	
Not sure/difficult to say	4	

ii) Hearing (If hearing aid is worn, code hearing with aid)

Normal	1	(28)
Poor	2	
Deaf	3	
Not sure/difficult to say	4	

13. Mobility

No difficulty walking	1	(29)
Walks without aid but with some difficulty	2	
Walks with aids (or mobile in wheelchair) indoors and out	3	
Unable to walk but can get around indoors	4	
Gets around with human aid only	5	
Immobile	6	

14. Continence.

Doubly incontinent	1	(30)
Incontinent (soiling or wetting) once a week or more	2	
Sometimes incontinent but less often than once a week	3	
Usually fully continent	4	

Does s/he show deliberate incontinence: that is, willful urination or defaecation in inappropriate places?

Never	1	(31)
Don't know, not sure	2	
Yes, isolated occasions only	3	
Yes	4	

15.	Self care skills. Does s/he perform the following tasks? i) Feeding Usually does so independently.....1 Physically capable but sometimes needs supervision.....2 With some assistance.....3 Completely dependent on others.....4	2	(32)
	ii)Washing Usually does so independently.....1 Physically capable but sometimes needs supervision.....2 With some assistance.....3 Completely dependent on others.....4	3	(33)
	iii) Dressing Usually does so independently.....1 Physically capable but sometimes needs supervision.....2 With some assistance.....3 Completely dependent on others.....4	4	(34)
	Does s/he show unwillingness to perform any of the self-care tasks listed above which s/he is potentially capable of doing? All or most of the time.....1 Sometimes.....2 Never, or hardly ever.....3	3	(35)
16.	Domestic skills - table laying, washing up etc. Works well with little or no supervision.....1 Sometimes with supervision.....2 No domestic skills.....3 Do not know or no opportunity.....4 → GO TO 17	3	(36)
	Does s/he show unwillingness to perform domestic tasks which s/he might otherwise be capable of doing? All or most of the time.....1 Sometimes.....2 Never, or hardly ever.....3	3	(37)
17.	Occupation. Occupies self constructively or can easily be occupied constructively.....1 Does not occupy self constructively, but cooperates in constructive activities.....2 Hard to keep occupied constructively may need one-to-one attention to keep occupied.....3 Never or, hardly ever possible to keep occupied constructively.....4	4	(38)

5

18.	Handling money. Could go shopping and check change..... Can use money, but not check change..... Realises money has value but does not use money..... Has no idea that money has value..... Don't know.....	1 2 3 4 5	(39)
19.	Communicative use of Speech and Gestures. Communicates regularly using varied phrases or sentences..... Only uses a few words, sounds or gestures as communication..... Little or no communication.....	1 2 3	(40)
20.	Understanding communication (ring the highest number which applies only) Understands little or nothing..... Understands a few simple commands (e.g. come here, sit down)..... Understands a fair range of instructions or questions related to practical needs..... Understands comments, questions and instructions related to personal needs and experiences (e.g. did you enjoy the trip to the zoo?)..... Understands information about things outside own immediate experience (e.g. stories or accounts of other peoples experiences).....	1 2 3 4 5	(41)
21.	Understanding of speech by others. Clear enough to be understood by anyone..... Can be understood by close acquaintances but difficult for strangers..... Difficult to understand, even by close acquaintances, impossible for strangers..... Not enough speech to rate.....	1 2 3 4	(42)

6

22. Stereotyped behaviour.

Does s/he engage in behaviour such as body rocking, finger tapping, hand waving, or other physical stereotyped behaviours? (Ring the first code which applies only)

Most of the time	1	(43)
At least daily	2	
At least weekly	3	
At least monthly	4	
Less Often	5	
Never	6	

23. Appropriacy of behaviour in interactions: With people who are well known to him or her.

No social responses	1	(44)
Interacts to satisfy own needs only	2	
Sometimes interacts appropriately but frequently does not	3	
Generally interacts appropriately but sometimes does not	4	
Almost always interacts appropriately	5	

24. Appropriacy of behaviour in interactions: With other people not well known.

No social responses	1	(45)
Interacts to satisfy own needs only	2	
Sometimes interacts appropriately but frequently does not	3	
Generally interacts appropriately but sometimes does not	4	
Almost always interacts appropriately	5	

25. Participation in group activities.

Initiates group activities (leads and organises)	1	(46)
Participates in group activities spontaneously and willingly	2	
Participates positively if encouraged to do so	3	
Actively disrupts group activities	4	
Does not participate in group activities - (an isolate)	5	
Varies too much to say	6	

Appendix 1

26. Friendships.

Does the person have any friends among the other residents/pupils/trainees? (Include anyone who as far as possible actively seeks and/or enjoys this person's company in a mutually rewarding way, including boyfriends and girlfriends).

No, no one	1	
Yes (at least one)	2	(47)
Do not know/cannot say	3	

27. How would you describe his/her relationships with other residents/pupils/trainees?

Indifferent	1	
Generally positive	2	(48)
Generally negative	3	
Mixed	4	
Other	5	

28. How would you describe his/her relationships with staff?

Indifferent	1	
Generally positive	2	(49)
Generally negative	3	
Mixed	4	
Other	5	

29. How often does s/he see a family member?
(Code first which applies)

Lives with family	1	
More than weekly	2	(50)
Weekly	3	
Once a month or more	4	
Once a year or more	5	
Less often	6	
Never	7	

8

Type(s) of behaviour problem displayed

Below will be found a number of descriptions of types of behaviour problem. For each problem there follows a set of different questions. Please show by ringing the correct number whether the type of problem indicated is:

1. One of this person's most serious management problems.

2. Present, but a lesser problem.

3. Previously or potentially a serious problem but controlled in this setting.

4. Not a problem for this person.

	Serious	Lesser	Controlled	No	
1. Physical attacks on other people	1	2	3	4	(51)
2. Self Injurious behaviour	1	2	3	4	(52)
3. Destructive behaviour	1	2	3	4	(53)
4. Other difficult, disruptive or socially unacceptable behaviour	1	2	3	4	(54)

FOR EACH PROBLEM RATED AS SERIOUS OR CONTROLLED PLEASE ANSWER THE APPROPRIATE QUESTIONS DEFINED AS FOLLOWS:

1. Physical attacks - questions on BLUE paper

2. Self injury - questions on YELLOW paper

3. Destructive behaviour - questions on GREEN paper

4. Other - questions on PINK paper

Appendix 2: Behavior Problems Inventory (Rojahn et al., 2001) (Chapter 4)

BPI

THE BEHAVIOR PROBLEMS INVENTORY
(BPI-01)

Name: _____

ID: _____

Date: _____

THE BEHAVIOR PROBLEMS INVENTORY

BPI

The Client

ID: _____ **Age**: _____ years _____ months **Gender**: ☐ male ☐ female

Ethnic Background: ☐ Euro-American ☐ African-American ☐ Asian/Pacific Islanders ☐ American Indian/Eskimo/Aleutian ☐ Hispanic-American ☐ Mixed ethnic background ☐ other/unknown/do not want to answer

Level of mental retardation:

IQ Test: ☐ Stanford Binet ☐ WISC-III ☐ WAIS-III ☐ Slosson ☐ Leiter-R ☐ other (please specify) _____ ☐ I don't know

IQ:_____ **Test date**:_____

☐borderline or above
☐mild mental retardation
☐moderate mental retardation
☐severe mental retardation
☐profound mental retardation
☐unknown

The Respondent

Please provide the following information about yourself

Relationship to the client: ☐ biological parent ☐guardian or foster parent ☐non-parental relative ☐day program staff/supervisor/teacher ☐psychologist ☐case manager ☐behavior specialist ☐other

Time typically spent with the client:(Days, weeks, or months): _____
Time you have you known the client: (Weeks, months, years) _____

Results

	Frequency scores	Degree of Problem scores
SIB		
Stereotyped Behavior		
Aggressive/Destructive Behavior		

Instructions

On the following pages you will find generic definitions followed by specific descriptions of three types of behavior problems: self-injurious behaviors (items 1-15), stereotyped behaviors (items 16-40), and aggressive/destructive behaviors (items 41-52).

Please indicate which behaviors you have observed in this individual during the past two months by circling the number in the appropriate boxes to indicate (a) how often the described behavior typically occurs (frequency) and (b) how much of a problem the behavior represents. If the behavior has never been observed during the last two months, circle the number "0".

Below are three examples for a person named Jane:

1. Jane has never been seen biting herself.
2. She does like to body rock. When unobserved, she does it almost constantly. However, it does not really cause any harm and Jane can be easily redirected.
3. Hitting others is a big concern with Jane. Although it does not happen very frequently (perhaps once week), this is a big concern. She has hit several other clients and has caused bruises once even chipped somebody's tooth.

	never	Frequency				Degree of Problem		
		monthly	weekly	daily	hourly	slight	moderate	severe
. Self-biting (so hard that a tooth print can be seen for ome time; bloodshot or breaking of skin may occur)	X	1	2	3	4	1	2	3
6. Rocking back and forth	0	1	2	3	*X*	*X*	2	3
1. Hitting others	0	1	*X*	3	4	1	2	*X*

SELF-INJURIOUS BEHAVIOR

Generic definition: ***Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.***

	never	Frequency				Degree of Problem		
		monthly	weekly	daily	hourly	slight	moderate	severe
. Self-biting (so hard that a tooth print can be seen for some time; bloodshot or breaking of skin may occur)	0	1	2	3	4	1	2	3
. Hitting head with hand or other body part (e.g., face slapping, knee against forehead) or with/against objects (e.g., slamming against a wall, knocking head with a toy)	0	1	2	3	4	1	2	3
. Hitting body (except for the head) with own hand or with any other body part (e.g., kicking self, slapping arms or thighs), or with/against objects (e.g., hitting legs with a stick, boxing the wall)	0	1	2	3	4	1	2	3
. Self-scratching (so hard that reddening of the skin becomes visible; breaking of the skin may also occur)	0	1	2	3	4	1	2	3
. Vomiting and rumination (deliberate regurgitation of swallowed food with rumination)	0	1	2	3	4	1	2	3
. Self-pinching (so hard that reddening of the skin becomes visible; breaking of the skin may occur)	0	1	2	3	4	1	2	3
. Pica: Mouthing or swallowing of objects which should not be mouthed or swallowed for health or hygiene reasons (non-food items such as feces, grass, paper, garbage, hair)	0	1	2	3	4	1	2	3
. Stuffing objects in body openings (in nose, ears, or anus, etc.)	0	1	2	3	4	1	2	3
. Pulling finger or toe nails	0	1	2	3	4	1	2	3
0. Stuffing fingers in body openings (e.g., eye poking, finger in anus)	0	1	2	3	4	1	2	3
1. Air swallowing resulting in extended abdomen	0	1	2	3	4	1	2	3
2. Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
3. Extreme drinking (e.g., more than 3 liters per day)	0	1	2	3	4	1	2	3
4. Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3
5. Other:	0	1	2	3	4	1	2	3
Add ratings for items 1 - 15				Frequency score			Degree of problem score	

STEREOTYPED BEHAVIOR

Generic definition: ***Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.***

	never	Frequency				Degree of Problem		
		monthly	weekly	daily	hourly	slight	moderate	severe
16. Rocking back and forth	0	1	2	3	4	1	2	3
17. Sniffing objects	0	1	2	3	4	1	2	3
18. Spinning own body	0	1	2	3	4	1	2	3
19. Waving or shaking arms	0	1	2	3	4	1	2	3
20. Rolling head	0	1	2	3	4	1	2	3
21. Whirling, turning around on spot	0	1	2	3	4	1	2	3
22. Engaging in repetitive body movements	0	1	2	3	4	1	2	3
23. Pacing	0	1	2	3	4	1	2	3
24. Twirling things	0	1	2	3	4	1	2	3
25. Having repetitive hand movements	0	1	2	3	4	1	2	3
26. Yelling and screaming	0	1	2	3	4	1	2	3
27. Sniffing own body	0	1	2	3	4	1	2	3
28. Bouncing around	0	1	2	3	4	1	2	3
29. Spinning objects	0	1	2	3	4	1	2	3
30. Having bursts of running around	0	1	2	3	4	1	2	3
31. Engaging in complex hand and finger movements	0	1	2	3	4	1	2	3
32. Manipulating objects repeatedly	0	1	2	3	4	1	2	3
33. Exhibiting sustained finger movements	0	1	2	3	4	1	2	3
34. Rubbing self	0	1	2	3	4	1	2	3
35. Gazing at hands or objects	0	1	2	3	4	1	2	3
36. Maintaining bizarre body postures	0	1	2	3	4	1	2	3
37. Clapping hands	0	1	2	3	4	1	2	3
38. Grimacing	0	1	2	3	4	1	2	3
39. Waving hands	0	1	2	3	4	1	2	3
40. Other	0	1	2	3	4	1	2	3
Add ratings for items 16 - 40				Frequency score		Degree of problem score		

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

Generic definition: ***Aggressive or destructive behaviors are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person.***

	Never	Frequency				Degree of Problem		
		monthly	weekly	daily	hourly	slight	moderate	severe
41. Hitting others	0	1	2	3	4	1	2	3
42. Kicking others	0	1	2	3	4	1	2	3
43. Pushing others	0	1	2	3	4	1	2	3
44. Biting others	0	1	2	3	4	1	2	3
45. Grabbing and pulling others	0	1	2	3	4	1	2	3
46. Scratching others	0	1	2	3	4	1	2	3
47. Pinching others	0	1	2	3	4	1	2	3
48. Spitting on others	0	1	2	3	4	1	2	3
49. Being verbally abusive with others	0	1	2	3	4	1	2	3
50. Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
51. Being mean or cruel (e.g., grabbing toys or food from others, bullying others)	0	1	2	3	4	1	2	3
52. Other:	0	1	2	3	4	1	2	3
Add ratings for items 41 - 52				Frequency score		Degree of problem score		

Appendix 3: Active Support Checklist (Chapter 4)

Behavioural Support Team Audit Tool

Name of Client: Name of Project

Completed by: Date:

Item	Present?	Comments
General Items		
1.Age-appropriateness of activities and materials		
2."Real" rather than pretend or very simple activities		
3.Choice of activities		
4.Demands presented carefully		
5.Tasks appropriately analysed to facilitate client involvement		
6.Sufficient staff contact for clients		
7.Graded assistance to ensure client success		
8.Speech matches developmental level of client		
9.Interpersonal warmth		
10. Differential reinforcement of adaptive behaviour		
11.Staff notice and respond to client communication		
12.Staff manage serious challenging behaviour well		
13.Staff work as a co-ordinated team to support clients		
14. Teaching embedded in everyday activities		
15.Specific written individual programmes in routine use		
Active Support Model		
1. Activity schedule for daily structured activities		
2.Communication guidelines and augmentative system		
3.Support protocols for presenting activities		
4.Opportunity plans		
5.Teaching plans		
6.Support plans for organising staff time		
7.Data collection for participation at home and in the community		
Behavioural Support		
1.Risk assessment and management strategies		
2.Behavioural support plan including diffusion and reactive strategies		
3.Behaviuor monitoring and data collection		
4.Incident reporting		
5.Formal debriefing and support process		
Miscellaneous		
1. Out of hours protocol		
2.Medication List and protocol		
3.Nursing Assessment		
4. Hep B info and Precautions		
5. Transition Plan		
6. Active Support Work books		

Appendix 4: Observation codes for resident and staff behaviours[1] (Chapter 4)

Resident Behaviours	Description
Social engagement	recognisable speech or attempts to speak, signs, gestures or other attempts to gain or maintain the attention of another person (except by challenging behaviour), or the giving of attention, as evidenced by eye contact or orientation of the head, to another person who is reciprocally interacting
Non-social engagement: domestic	getting ready for, doing or clearing away a household or gardening activity (e.g. washing clothes or setting the table)
Non-social engagement: personal	getting ready for, doing or clearing away a self-help or personal activity (e.g. eating or drinking)
Non-social engagement: other	getting ready for, doing or clearing away a recreational activity (e.g. looking at a magazine) or educational activity, the content of which could not be coded under the two codes above (e.g. matching colours)
Challenging behaviour	self-injury, aggression to others, damage to property, stereotypy or other inappropriate behaviours (e.g. public masturbation, stripping, spitting, pica, tugging at someone or pestering/pushing/pulling a person)
Staff Behaviours	
Verbal assistance	explicit instruction to perform activity (e.g. 'pick up the spoon'), or implicit instruction (e.g. questions about what step of the activity comes next)
Nonverbal assistance	gestural prompting of activity (e.g. pointing to the tin to be put in the cupboard), presentation of materials in the context of activity (e.g. handing a resident a towel to dry their hands), or demonstration (e.g. showing the person what to do and then prompting him or her gesturally to do it)
Physical assistance	physical prompting or guidance (e.g. giving hand over hand guidance as a resident pours a cup of tea), and guiding or arranging the materials being used by the resident in an activity (e.g. holding an item steady on a chopping board as a resident cuts it)
Praise	verbal, gestural or physical praise (e.g. saying 'Good!', signing 'That's right' or patting a resident on the back). Only coded when praise given for shaping behaviour. One key press for one episode of praise given for one behaviour
Negative/restraint	physical or verbal disapproval without correction, or physically preventing activity (e.g. saying 'No', holding a resident's hands down, or saying the resident's name in a controlling manner)
Other interaction	all other interactions neither encouraging nor discouraging of activity (e.g. pleasantries)
Feeding	feeding the resident with no attempt to encourage his or her participation in the task
Processing	doing something to a resident without assisting their participation (e.g. dressing a resident or holding a resident by

	the hand while walking)
Composite variables of resident behaviours	
Non-social engagement	combination of engagement in domestic, personal and other (educational or recreational) activities
Total engagement	combination of engagement in non-social and social activities
Challenging behaviour	combination of self-injury, stereotypy, aggression and other inappropriate behaviour (there were no instances of property destruction)
Composite variables of staff behaviours	
Total contact	combination of all staff behaviours
Total nonverbal assistance	combination of nonverbal and physical assistance
Total assistance	combination of total nonverbal and verbal assistance

[1] The observation protocol was provided by Prof. David Felce (Welsh Centre for Learning Disabilities, Cardiff) and the definitions were slightly adjusted for the purposes of this study (Chapter 4)

Appendix 5: Active Support Measure (ASM; Mansell & Elliott, 1996) (Chapter 4)

	1	2	3	4	5	6	7
Age-appropriateness							
0 Eg Not applicable because no activities provided							
1 Eg Most client activities/materials are childish eg form-boards, building bricks							
2 Eg Childish and adult client activities and materials equally represented							
3 Eg Most client activities and materials are adult							
'Real' activities							
0 Eg Not applicable because no activities provided							
1 Eg Most client activities are pretend or make-work (eg staff redo task afterwards)							
2 Eg Most client activities are real, but very simple (eg getting out and putting away)							
3 Eg Most client activities are real and include complex client activities like cooking, using equipment							
Choice of activities							
0 Eg Not applicable because no activities provided							
1 Eg Client activities vary over time but no choice							
2 Eg Choice of activities offered to clients at start but then clients expected to stick at it							
3 Eg More than one activity going on at a time and clients move between them when ready							
Demands presented carefully							
0 Eg Not applicable because no activities provided							
1 Eg Activities not prepared (so clients kept waiting or have 'false starts') or clumsily presented (eg too tentative or too oppressive).							
2 Eg Some demands presented appropriately but many mistakes							
3 Eg Materials well prepared and tasks presented using appropriate communication eg handing materials, gestures as well as speech.							
Tasks appropriately analysed							
0 Eg Not applicable because no activities provided							
1 Eg Most opportunities to involve clients (eg in simple parts of tasks) missed							
2 Eg Some opportunities to involve clients (eg in simple parts of tasks) taken but many missed							
3 Eg Most opportunities to involve clients (eg in simple parts of tasks) taken							
Sufficient staff contact							
0 Eg Clients typically left alone by staff							
1 Eg Occasional contact from staff							
2 Eg Moderate levels of contact from staff but many instances where needed support is not immediately available because staff are otherwise occupied							
3 Eg Help and support for clients of all levels of disability always on hand							
Graded assistance to ensure client success							
0 Eg Not applicable because no assistance provided							
1 Eg Occasional assistance from staff or assistance of only one level (eg instructions) provided							
2 Eg Moderate levels of assistance from staff but many instances where needed assistance not given (missing or wrong level of assistance given)							
3 Eg Graded assistance frequently given							
Speech matches developmental level of client							
0 Eg Not applicable because no speech provided							
1 Eg Most speech much too complicated or much too simple for client ability level							
2 Eg Some speech matches client ability level but some too complicated or too simple							
3 Eg Most speech matches client ability level							
Interpersonal warmth							
0 Eg Not applicable because no interaction							
1 Eg Interactions typically cold, formal and/or disrespectful (eg teasing, offensive)							
2 Eg Mixed interactions (perhaps because staff differ)							
3 Eg Most interactions warm and respectful							

Differential reinforcement of other behaviour

If no variety of client behaviour (eg always passive) please tick here: ☐

0 Eg Not applicable because no contact provided

1 Eg Most staff attention contingent on maladaptive behaviour

2 Eg Apparently near-random allocation of staff attention

3 Eg Most staff attention contingent on adaptive behaviour

Staff notice and respond to client communication

0 Eg Not applicable because no contact provided by staff

1 Eg Few attempts by clients to communicate responded to by staff

2 Eg Some communication responded to but some overlooked or ignored

3 Eg Most attempts to communicate by clients noticed and responded to

Staff manage serious challenging behaviour well

0 Eg Not applicable because no attempted aggression or self-injury or significant property damage (eg smashing, breaking)

1 Eg Major disruption caused by challenging behaviour; staff responses either uncoordinated, ineffective or punitive

2 Eg Staff cope moderately well

3 Eg Staff manage challenging behaviour well; respond effectively, non-punitively, in a co-ordinated way and do not allow challenging behaviour to disrupt flow of activity

Staff work as a team

0 Eg Staff apparently uncoordinated, working as individuals

1 Eg Staff work to a rigid timetable irrespective of client needs or circumstances

2 Eg Staff plan as they go, co-ordinating and liaising but not planning ahead. Clients are sometimes accidentally lost between staff, activities overlooked.

3 Eg Staff plan what they do in advance and adjust plan to reflect client needs. Clients pass from one activity to another without big gaps and with support they need available to them

Teaching embedded in everyday activities

0 Eg Not applicable because no teaching or no activities

1 Eg Most opportunities to teach clients incidentally missed

2 Eg Some opportunities to teach clients incidentally missed

3 Eg Most opportunities to teach clients incidentally taken

Specific, written individual programmes in routine use

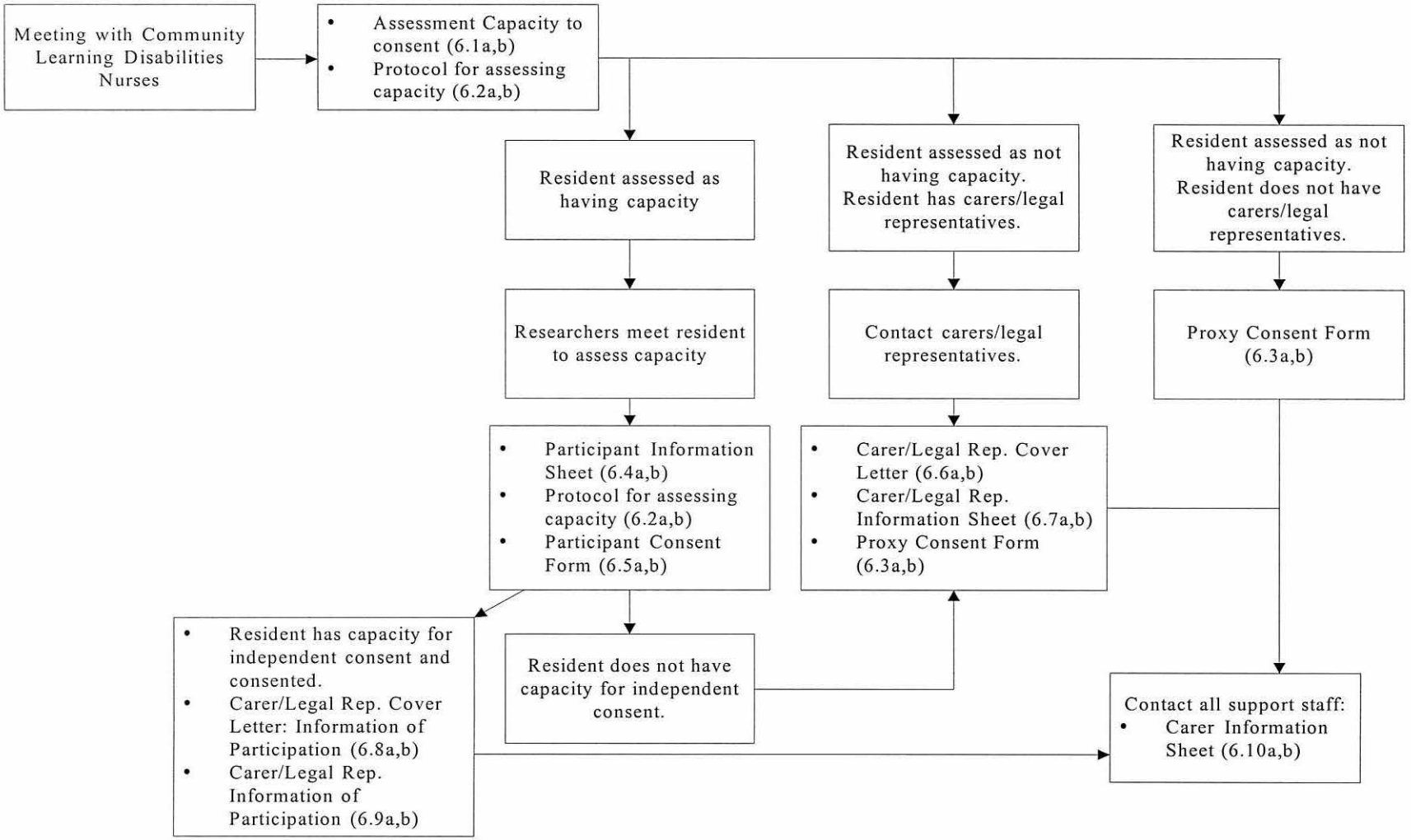
0 Eg No written individual programmes (eg for teaching, behaviour management or therapy) in use

1 Eg One or two written programmes observed in use

2 Eg Some written programmes observed in use

3 Eg Written programmes extensively observed in use

Appendix 6: Procedure and documents used for the consent procedure with study participants in Chapter 4



6.1a: Assessment Capacity to Consent-English

Participant Identification Number for this trial:

PARTICIPANT'S CAPACITY TO CONSENT

Date: 12 May 2005
Version 1.1

The effects of Active Support Interactive Training in the daily activities of adults with a learning disability in residential services

Your client is being invited to take part in a research study. We would like to assess the capacity of the client to consent for participation to the research study independently. Please indicate whether the client:

1. Is able to comprehend and retain information material to the decision:
   Yes ☐ , No ☐
2. Is able to use and weigh this information in the decision-making process:
   Yes ☐ , No ☐

If you have answered No to one of the above statements, then the client is judged to lack the capacity to give or withhold consent to the proposed research procedure. Please find attached a protocol (Protocol for Capacity) which the researchers will use if the answers to the questions above are "Yes". This protocol assesses the capacity of the client to consent to the specific research procedure.

Please read the protocol.

3. Do you think that the client will be able to complete the procedure described in the protocol?
   Yes ☐ , No ☐ , Not sure ☐

If your answers to questions 1 and 2 are No and to question 3 is No or Not sure, then the researchers will contact the client's legal representatives.

Name of Community Residential Service Nurse:_____

Signature:_____
Date: _____

Name of Researcher: _____

Signature:_____
Date:_____

6.1b: Assessment Capacity to Consent-Welsh

Rhif Adnabod y Cyfranogwr ar gyfer y prawf hwn:

GALLU CYFRANOGWR I GYDSYNIO

Dyddiad: 12 Mai 2005
Fersiwn 1.1

Effeithiau Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol ar weithgareddau beunyddiol oedolion ag anabledd dysgu mewn gwasanaethau preswyl

Mae gwahoddiad i'ch cleient gymryd rhan mewn astudiaeth ymchwil. Hoffem asesu gallu'r cleient i gydsynio i gymryd rhan yn yr astudiaeth ymchwil yn annibynnol. Nodwch a yw'r cleient:

4. Yn gallu deall a chadw gwybodaeth sy'n berthnasol i'r penderfyniad:
   ✓☐ , ×☐

5. Yn gallu defnyddio a phwyso a mesur y wybodaeth hon wrth wneud penderfyniadau:
   ✓☐ , ×☐

Os ydych wedi ateb un o'r gosodiadau isod yn negyddol, bernir nad yw'r cleient yn gallu cydsynio neu beidio â chydsynio i drefn yr ymchwil arfaethedig. Rydym yn amgáu protocol (Protocol ynglŷn â Gallu) y bydd yr ymchwilwyr yn ei ddefnyddio os bydd yr atebion i'r cwestiynau uchod yn gadarnhaol. Mae'r protocol hwn yn asesu gallu'r cleient i gydsynio i drefn benodol yr ymchwil.

Darllenwch y protocol.

6. A ydych yn credu y bydd y cleient yn gallu dilyn y drefn a ddisgrifir yn y protocol?
   ✓☐ , ×☐ , Ansicr☐

Os ydych wedi ateb cwestiynau 1 a 2 yn negyddol, ac wedi rhoi × neu 'Ansicr' wrth gwestiwn 3, bydd yr ymchwilwyr yn cysylltu â chynrychiolwyr cyfreithiol y cleient.

Enw'r Nyrs Gwasanaeth Preswyl Cymuned:_____

Llofnod: _____
Dyddiad: _____

Enw'r Ymchwilydd: _____

Llofnod: _____
Dyddiad: _____

6.2a: Protocol for Assessing Capacity-English

Participant Identification Number for this trial:

Protocol for determining capacity to consent in cases where the Community Residential Nurse has confirmed the individual's capacity to give or withhold consent.

Date: 12 May 2005
Version 1.1

1. Read Information sheet once to participant

2. Read the following part of the Information sheet: "We know that it is very important for everyone to do things that are fun. We are interested in the things you do in your house every day, like making breakfast and cleaning. I want to come to your house and see the things that you do with staff."

   Ask the participant: "**Why do I want to come to your house?**".
   Score 1 if the person gives an answer similar to "To see the things I do with staff" or "To see what I do".
   Score 0 if the answer is irrelevant or too vague (eg "See me").

3. Read the following part of the Information sheet: "I would like to come four times".

   Ask the participant: "**How many times will I come to your house?**".
   Score 1 for correct number of times and 0 for incorrect number of times.

4. Read the following part of the Information sheet: "I also want to ask staff some things about you. These things are: Things that you are good at, and things you are not so good at, times when staff are worried about you, how old you are."

   Ask the participant: "**What do I want to ask staff about you?**".
   Score 1 for any answer similar to "Me" or "Things I am good at" or "Things I am not so good at" or "When staff are worried about me" or "How old I am".
   Score 0 if the answer is too vague or irrelevant.

5. Read the following part of the Information sheet: "When I have finished, the things I'll see and the answers I get from staff will be kept in a safe place. Remember that you do not have to say yes. If you do not want me to come to your house or ask staff about you, just say no."

   Ask the participant "**Are you happy for me to come to your house and watch what you do?**" Answers Yes or No.

Ask the participant: "**Are you happy for me to ask staff things about you?.**
Answers Yes or No.
For consent to be given the participant needs to answer Yes to both questions.

6. Read the following part of the Information sheet: "If you say yes, but then you change your mind that's OK. Just tell me no later on. You won't have to tell me why"

   Ask the participant: "**What will you do if you change your mind?**".
   Score 1 for any answer similar to "Tell you No".
   Score 0 if answer is irrelevant or too vague.

Overall Scoring
If the participant scores 0 to any of the questions under items 2,3,4 or 6, then the participant is assessed as not having the capacity to consent in this specific context and the researchers should follow the alternative route of seeking consent through the legal representatives. If the participant scores 1 in every question under items 2,3,4 and 6 and answers "Yes" to both questions under item 5, then the participant is assessed as having the capacity to consent and s/he is indicating his wish to participate. If the participant scores 1 in every question under items 2,3,4 and 6 but answers "No" in either question 5, the participant is assessed as having the capacity to consent and is indicating his refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11* (1), 77-83.

6.2b: Protocol for Assessing Capacity-Welsh

Rhif Adnabod y Cyfranogwr ar gyfer y prawf hwn:

Protocol ar benderfynu a all cleient gydsynio mewn achosion lle bo'r Nyrs Preswyl Cymuned wedi cadarnhau fod gan yr unigolion y gallu i gydsynio neu i beidio.

Dyddiad: 12 Mai 2005
Fersiwn 1.1

1. Darllenwch y wybodaeth unwaith wrth y cyfranogwr.

2. Darllenwch y darn isod o'r Daflen Wybodaeth: "Rydym yn gwybod ei bod yn bwysig iawn i bawb wneud pethau sy'n bleserus. Mae gennym ddiddordeb yn y pethau y byddwch yn eu gwneud yn eich tŷ bob dydd, megis gwneud brecwast a glanhau. Hoffwn ddod draw i'ch tŷ a gweld y pethau y byddwch yn eu gwneud gyda'r staff."

   Holwch y cyfranogwr: "**Pam rwyf am ddod draw i'ch tŷ?**".
   Sgoriwch 1 os bydd yr unigolyn yn rhoi ateb megis "I weld y pethau y byddaf yn eu gwneud gyda'r staff" neu "I weld be' allaf ei wneud".
   Sgoriwch 0 os bydd yr ateb yn amherthnasol neu heb fod yn ddigon clir (e.e. "I 'ngweld").

3. Darllenwch y darn isod o'r Daflen Wybodaeth: "Hoffwn ddod draw bedair gwaith."

   Holwch y cyfranogwr: **"Sawl gwaith y byddaf yn dod draw i'ch tŷ?".**
   Sgoriwch 1 am y nifer gywir o weithiau a 0 am nifer anghywir o weithiau.

4. Darllenwch y darn isod o'r Daflen Wybodaeth: "Rwyf hefyd yn awyddus i ofyn i'r staff rai cwestiynau amdanoch chi, sef: Pethau rydych yn eu gwneud yn dda, a phethau dydych chi ddim yn cael cystal hwyl arnynt, adegau y mae'r staff yn poeni amdanoch, faint yw eich oedran."

   Holwch y cyfranogwr: **"Beth rwyf am ei ofyn i'r staff amdanoch chi?"**
   Sgoriwch 1 am unrhyw ateb sy'n debyg i "Fi" neu "Pethau dwi'n eu gwneud yn dda" neu "Pethau dwy ddim yn eu gwneud cystal" neu "Pan fydd staff yn poeni amdana' i" neu "Fy oedran".
   Sgoriwch 0 os bydd yr ateb yn amherthnasol neu heb fod yn ddigon clir.

5. Darllenwch y darn isod o'r Daflen Wybodaeth: "Pan fyddaf wedi gorffen, caiff y pethau a welaf a'r atebion a gaf oddi wrth y staff eu cadw mewn lle diogel. Cofiwch nad oes raid ichi ddweud ie. Os nad ydych am imi ddod draw i'ch tŷ na holi'r staff amdanoch, dywedwch na."

Gofynnwch i'r cyfranogwr, "**Ydych chi'n fodlon imi ddod draw i'ch tŷ a gweld be' fyddwch chi'n ei wneud?**" Atebion Ydw neu Nac ydw.
Holwch y cyfranogwr: "**A ydych chi'n fodlon imi holi'r staff amdanoch?**".
Atebion Ydw neu Nac ydw.
Er mwyn rhoi cydsyniad, rhaid i'r cyfranogwr ateb y ddau gwestiwn yn gadarnhaol.

6. Darllenwch y darn isod o'r Daflen Wybodaeth: "Os dywedwch ie, ond ail-feddwl wedyn, mae hynny'n iawn. Dywedwch wrthyf wedyn. Fydd dim rhaid ichi ddweud wrthyf pam."

   Holwch y cyfranogwr: "**Beth fyddwch yn ei wneud os newidiwch eich meddwl?**".
   Sgoriwch 1 am unrhyw ateb sy'n debyg i "Dweud Na wrthych chi".
   Sgoriwch 0 os bydd yr ateb yn amherthnasol neu heb fod yn ddigon clir.

Sgorio Cyffredinol
Os bydd y cyfranogwr yn sgorio 0 i unrhyw un o'r cwestiynau dan eitemau 2, 3, 4 neu 6, yna bernir nad yw'r gallu gan y cyfranogwr i gydsynio yn y cyd-destun penodol hwn, a dylai'r ymchwilwyr ddilyn y llwybr amgen o geisio cydsyniad trwy'r cynrychiolwyr cyfreithiol. Os bydd y cyfranogwr yn sgorio 1 ym mhob cwestiwn dan eitemau 2, 3, 4 a 6, ac yn ateb y ddau gwestiwn dan eitem 5 yn gadarnhaol, bernir fod y gallu gan y cyfranogwr i gydsynio a'i b/fod yn dangos ei dymuniad i gymryd rhan. Os bydd y cyfranogwr yn sgorio 1 ym mhob cwestiwn dan eitemau 2, 3, 4 a 6, ond yn ateb y naill gwestiwn neu'r llall dan eitem 5 yn negyddol, bernir fod y gallu gan y cyfranogwr i gydsynio a'i b/fod yn dangos nad yw'n dymuno cymryd rhan.

Mae'r protocol hwn yn seiliedig ar y drefn a ddilynir gan Arscott, Dagnan a Kroese, 1998.

Arscott, K., Dagnan, D., a Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11* (1), 77-83.

6.3a: Proxy Consent for Participant-English

Centre Number:
Study Number:
Participant Identification Number for this trial:

Proxy Consent Form for Participant

Version 1.1

The effects of Active Support Interactive Training in the daily activities of adults with a learning disability in residential services.

Name of researchers: Jonathan McCarthy and Vasiliki Totsika, supervised by Prof. Richard Hastings, Dr Sandy Toogood and Dr Carl Hughes.

Please initial box

O I confirm that I have read and understand the information sheet dated ...../...../..... (version.....) for the above study and have had the opportunity to ask questions.

O I understand that participation is voluntary and that I am free to withdraw my relative/client at any time without giving any reason. This will not affect care or legal rights of my relative/client.

O I therefore agree on behalf of ..... that researchers can visit the house for observations and a member of staff can be contacted for information.

Name of person giving consent	Date	Signature
Relationship to participant	Contact details	
Researcher	Date	Signature

6.3b: Proxy Consent for Participant-Welsh

Rhif y Ganolfan:
Rhif yr Astudiaeth:
Rhif Adnabod y Cyfranogwr ar gyfer y prawf hwn:

Ffurflen Gydsynio trwy Ddirprwy dros Gyfranogwr

Fersiwn 1.1

Effeithiau Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol ar weithgareddau beunyddiol oedolion ag anabledd dysgu mewn gwasanaethau preswyl.

Enw'r ymchwilwyr: Jonathan McCarthy a Vasiliki Totsika, dan oruchwyliaeth yr Athro Richard Hastings, Dr Sandy Toogood a Dr Carl Hughes.

Rhowch lythrennau blaen eich enw yn y bylchau

☐ Cadarnhaf fy mod wedi darllen a deall y daflen wybodaeth ddyddiedig ...../...../..... (fersiwn .....) ynglŷn â'r astudiaeth uchod, ac wedi cael cyfle i ofyn cwestiynau.

☐ Deallaf fy mod yn cyfranogi o'm gwirfodd, a bod gennyf hawl i dynnu fy mherthynas / fy nghleient yn ôl ar unrhyw adeg heb roi unrhyw reswm. Ni fydd hyn yn effeithio ar safon gofal na hawliau fy mherthynas / fy nghleient.

☐ Cytunaf, felly, ar ran ..... y caiff ymchwilwyr ymweld â'r tŷ i arsylwi ac y gellir cysylltu ag aelod o'r staff am gwybodaeth.

Enw'r sawl sy'n rhoi cydsyniad	Dyddiad	Llofnod
Perthynas â'r cyfranogwr	Manylion cyswllt	
Ymchwilydd	Dyddiad	Llofnod

6.4a: Participant Information Sheet-English

Participant Information Sheet

Date: 21 June 2005
Version: 1.2

Doing Things with Staff

We know that it is very important for everyone to do things that are fun. We are interested in the things you do in your house every day, like making breakfast and cleaning.

I want to come to your house and see the things that you do with staff. I would like to come six times. I also want to ask staff some things about you. These things are:

- Things that you are good at, and things you are not so good at
- Times when staff are worried about you
- How old you are

When I have finished, the things I'll see and the answers I get from staff will be kept in a safe place.

Remember that you do not have to say yes. If you do not want me to come to your house or ask staff about you, just say no.

If you say yes, but then you change your mind that's OK. Just tell me no later on. You won't have to tell me why.

Thank you for letting me read this to you.

6.4b: Participant Information Sheet-Welsh

Taflen Wybodaeth i Gyfranogwyr

Dyddiad: 21 Mehefin 2005
Fersiwn: 1.2

Gwneud Pethau gyda'r Staff

Rydym yn gwybod ei bod yn bwysig iawn i bawb wneud pethau sy'n bleserus. Mae gennym ddiddordeb yn y pethau y byddwch yn eu gwneud yn eich tŷ bob dydd, megis gwneud brecwast a glanhau.

Hoffwn ddod draw i'ch tŷ a gweld y pethau y byddwch yn eu gwneud gyda'r staff. Hoffwn ddod draw chwe gwaith. Rwyf hefyd yn awyddus i ofyn rhai cwestiynau amdanoch i'r staff, sef:

- Pethau rydych yn eu gwneud yn dda, a phethau dydych chi ddim yn cael cystal hwyl arnynt
- Adegau y mae'r staff yn poeni amdanoch
- Faint yw eich oedran

Pan fyddaf wedi gorffen, byddaf yn cadw gwybodaeth am y pethau a welaf a'r atebion a gaf oddi wrth y staff mewn lle diogel.

Cofiwch nad oes raid ichi ddweud ie. Os nad ydych am imi ddod draw i'ch tŷ na holi'r staff amdanoch, dywedwch na.

Os dywedwch ie, ond ail-feddwl wedyn, mae hynny'n iawn. Dywedwch wrthyf wedyn. Fydd dim rhaid ichi ddweud wrthyf pam.

Diolch am adael imi ddarllen hwn ichi.

6.5a: Participant Consent Form-English

Centre Number:
Study Number:
Participant Identification Number for this trial:

Participant Consent Form

Version 1.2

Doing Things with Staff

I am interested in the things that you do in your house every day with staff.

To find out about this I need to visit your house 6 times and ask staff who know you well to tell me about your life there.

Are you happy for me to visit and ask staff about you?

I have witnessed that..... has orally consented for researchers to visit the house for observations and ask member of staff to provide information.

Witnessed by (sign):.....

Date:...../...../.....

Name in capitals:.....

Address and/or contact number:
.....

Researcher's name:.....

Researcher's signature:.....

6.5b: Participant Consent Form-Welsh

Rhif y Ganolfan:
Rhif yr Astudiaeth:
Rhif Adnabod y Cyfranogwr ar gyfer y prawf hwn:

Ffurflen Gydsynio i Gyfranogwyr

Fersiwn 1.2

Gwneud Pethau gyda'r Staff

Mae gennyf ddiddordeb yn y pethau y byddwch yn eu gwneud yn eich tŷ bob dydd gyda'r staff.

I gael gwybod am hyn, mae angen imi ymweld â'ch tŷ 6 gwaith a gofyn i'r staff sy'n eich adnabod yn dda ddweud wrthyf am eich bywyd yno.

A ydych yn fodlon imi ddod draw a holi'r staff amdanoch?

Rwyf yn dyst fod..... wedi cydsynio ar lafar i ymchwilwyr ymweld â'r tŷ i arsylwi ac o ofyn i aelodau'r staff roi gwybodaeth.

Tystiwyd gan (llofnod).....

Dyddiad ...../...../.....

Enw mewn priflythrennau .....

Cyfeiriad a/neu rif cyswllt:
.....

Enw'r ymchwilydd: .....

Llofnod yr ymchwilydd: .....

6.6a: Carer/Legal representative cover letter-English

Carer/Legal Representative Covering Letter

Date: 22 March 2005
Version: 1.1

Dear ,

We are currently carrying out a study on the quality of life of adults with a learning disability who live in residential accommodation. The focus of the study is on the way staff training impacts on the daily activities of residents and on their problem behaviour. This study is collaboration between the University of Wales, Bangor and Intensive Support Services, North East Wales NHS Trust.

We would like to invite to participate in the study. We would be grateful if you would read the information sheet attached to this letter and decide whether participation in this study is in the best interests of .

Thank you for taking the time to consider this.

Yours Sincerely,

Vasiliki Totsika (PhD student) and Jonathan McCarthy (MSc student)

6.6b: Carer/Legal representative Cover Letter-Welsh

Llythyr Ategol i Ofalwyr / Cynrychiolwyr Cyfreithiol

Dyddiad: 22 Mawrth 2005
Fersiwn: 1.1

Annwyl ,

Rydym wrthi ar hyn o bryd yn cynnal astudiaeth ar ansawdd bywyd oedolion ag anabledd dysgu sy'n byw mewn cartrefi preswyl. Canolbwynt yr astudiaeth hon yw'r modd y mae'r hyfforddiant a gaiff y staff yn effeithio ar weithgareddau beunyddiol y preswylwyr ac ar eu hymddygiad problemus. Gwaith ar y cyd yw'r astudiaeth hon rhwng Prifysgol Cymru, Bangor a'r Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru.

Hoffwn wahodd i gymryd rhan yn yr astudiaeth. Byddem yn ddiolchgar pe baech yn darllen y daflen wybodaeth sydd ynghlwm wrth y llythyr hwn a phenderfynu a fyddai cymryd rhan yn yr astudiaeth er pennaf les .

Diolch am roi o'ch amser i ystyried y mater hwn.

Yn gywir,

Vasiliki Totsika (myfyrwraig PhD) a Jonathan McCarthy (Myfyriwr MSc)

6.7a: Carer/Legal Representative Information Sheet-English

Carer/Legal Representative Information Sheet

Date: 21 June 2005
Version: 1.2

The effects of Active Support Interactive Training in the daily activities of adults with a learning disability in residential services.

Your relative/client is being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and/or a relevant professional if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Health Research and You'. This leaflet gives more information about health research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW or online at www.ceres.org.uk/order.htm

What is the purpose of the study?
The aim of the study is to investigate the effects that staff training has on the quality of life of adults with a learning disability in residential settings. Care staff who work in the houses managed by Community Residential Services, North East Wales (NEW) NHS Trust, will receive interactive training on Active Support by Intensive Support Services NEW NHS, as part of their ongoing service development.

Our study is interested in seeing how this training impacts on the daily activities of the house residents in terms of their engagement in activities and problem behaviour.

How have I been contacted?
Permission to contact you was granted by the manager of Community Residential Service who provided us with your contact information. As the legal representative of the house resident, we would like to ask you to consider whether participation in this study is in the best interests of your relative/client.

What will happen to my relative/client if I consent for their participation?
A researcher will visit the house to observe the daily activities of the residents on three occasions. Once before staff receive the interactive training and once again a month after the training ends. The third visit will take place approximately six months after staff complete their training. Two house visits are scheduled for every occasion, each of which will last three hours. Researchers will conduct real-time observations of residents' engagement in activities, their interactions with staff members and their problem behaviour. In addition, a researcher will meet with a member of staff, who knows the resident well, in order to fill in three rating scales related to the resident's ability skills and problem behaviour. Throughout the study researchers will not interact directly with the residents, there will always be a member of staff present and

observations will not take place in private places, such as the bedrooms or the bathroom.

Will participation be confidential?
Information gathered through the observations and the rating scales will be treated with the strictest confidence. In order to ensure anonymity, each resident will be assigned a number code which will appear on any files thereafter, so that electronic or hard copy data do not identify residents or care staff. The hard copies of the rating scales and the list that links residents' names to their number codes will be kept locked safely in the University of Wales, Bangor and will be destroyed at the end of the study. Electronic data files which will contain anonymous, non-identifiable information will be kept indefinitely as part of ongoing research.

What if I do not wish for my relative/client to participate?
You are under no obligation to consent for your relative/client's participation and are free to choose not to. If you do decide to consent on behalf of your relative/client, you will keep this information sheet and you will be asked to sign a consent form –a copy of which you are going to keep. If you give your consent but at any point during the study change your mind, you are free to withdraw your relative/client from the study without giving us a reason.

How will this study benefit my relative/client?
If the present study suggests that Active Support benefits house residents then this programme will be further developed to suit the needs of the people living in the houses. A number of studies conducted by other researchers suggest that when care staff receive training on Active Support, there are a number of direct benefits for residents. They participate in more activities on a daily basis, they have more social interactions and they receive more efficient support and assistance from staff. In this way, residents develop their competencies, become more autonomous and can exercise individual choice. As an example, previous studies have found that after Active Support the amount of time residents spend engaged in an activity increases by about 20% (from about 30% to 50% approx). In a 16-hr day this is equivalent to more than 3 hours of doing things, which is a substantial increase. Increased engagement/activity contributes to quality of life and physical well-being.

What if something goes wrong during the study?
To the best of our knowledge, there were no issues arising in previous studies and we do not anticipate any difficulties. The observational protocol has been designed to minimise inconvenience to the residents and the researchers will visit the houses to familiarise with the residents before the study begins. Members of staff will always be present in the house when researchers are there. In addition, researchers are supervised by academic supervisors who are highly experienced in working and doing research with adults with a learning disability. Researchers' work will be monitored weekly by their supervisors.

What will happen with the results of this study?
The results of this study will be presented for participants as a group and no mention to individuals' data will take place. The results will be presented to Community Residential Service managers, staff and clients, where applicable. Findings will form

part of two educational qualifications: a PhD and a MSc, copies of which will be given to the Library of the University of Wales, Bangor. Publications in scientific journals and presentations in conferences will also be given.

Who has reviewed this study?
The project has been reviewed by North East Wales Local Research Committee and by the Ethics Committee of the School of Psychology, University of Wales, Bangor.

Who are the researchers?
There are two researchers involved in the study:
Vasiliki Totsika, PhD Student, and Jonathan McCarthy, MSc Student. Both researchers study at the School of Psychology, University of Wales, Bangor.
Jonathan is a Behavioural Advisor and Vasiliki is an Honorary Research Assistant at Intensive Support Services, North East Wales, NHS trust.

They are supervised by:
- Prof. Richard Hastings, Professor of Psychology and Deputy Head of School of Psychology, University of Wales, Bangor
- Dr Sandy Toogood, Consultant Behaviour Analyst, Intensive Support Services, North East Wales NHS, and Senior Research Fellow, School of Psychology, University of Wales, Bangor
- Dr Carl Hughes, Teaching Fellow, School of Psychology, University of Wales, Bangor

Contacts for further information:
Vasiliki Totsika, School of Psychology, University of Wales, Bangor
Adeilad Brigantia,Bangor, Gwynedd LL57 2AS
Tel: 01248 351151 ext.: 8706
Email: psp047@bangor.ac.uk

Jonathan McCarthy, Intensive Support Services, Trinity House, Trinity Road Wrexham LL11 1NL
Tel: 01978 290020
Email: JONATHAN.MCCARTHY@new.tr-wales.nhs.uk

If you have any complaints about how this study is conducted please address these to either of the persons below:

Deputy Head of School School of Psychology University of Wales, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Chief Executive North East Wales NHS Trust Wrexham Maelor Hospital Croesnewydd Road Wrexham, LL13 7TD

Thank you very much for taking the time to read this.

6.7b: Carer/Legal representative Information Sheet-Welsh

Taflen Wybodaeth i Ofalwyr / Cynrychiolwyr Cyfreithiol

Dyddiad: 21 Mehefin 2005
Fersiwn: 1.2

Effeithiau Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol ar weithgareddau beunyddiol oedolion ag anabledd dysgu mewn gwasanaethau preswyl.

Mae gwahoddiad i'ch perthynas/cleient gymryd rhan mewn astudiaeth ymchwil. Cyn ichi benderfynu a ydych am gymryd rhan neu beidio, mae'n bwysig eich bod yn deall y rheswm am wneud yr ymchwil a'r hyn y bydd yn ei olygu. Cymerwch amser i ddarllen y wybodaeth isod yn ofalus a'i thrafod â ffrindiau, perthnasau a/neu â gweithiwr proffesiynol perthnasol os dymunwch. Holwch ni os ydych yn ansicr ynglŷn â rhywbeth, neu os hoffech gael mwy o wybodaeth. Cymerwch amser i benderfynu p'un a hoffech gymryd rhan neu beidio.

Mae Consumers for Ethics in Research (CERES) wedi cyhoeddi taflen yn dwyn y teitl 'Health Research and You'. Mae'r daflen hon yn rhoi mwy o wybodaeth ynglŷn ag ymchwil iechyd ac yn edrych ar rai cwestiynau y gallech fod yn awyddus i'w gofyn. Cewch gopi gan CERES, PO Box 1365, Llundain N16 0BW neu ar-lein ar www.ceres.org.uk/order.htm

Beth yw diben yr astudiaeth?
Amcan yr astudiaeth yw ymchwilio i'r effeithiau a gaiff hyfforddiant staff ar ansawdd bywyd oedolion ag anabledd dysgu mewn cartrefi preswyl. Bydd staff gofal sy'n gweithio yn y tai a reolir gan Wasanaethau Preswyl Cymunedol, Ymddiriedolaeth Iechyd Gogledd-Ddwyrain Cymru yn derbyn hyfforddiant rhyngweithiol ar Gynhaliaeth Weithredol trwy Wasanaethau Cynnal Dwys yr Ymddiriedolaeth honno, a hynny fel rhan o'u datblygiad proffesiynol parhaus.

Wrth inni gynnal yr astudiaeth hon, mae gennym ddiddordeb mewn canfod sut y mae'r hyfforddiant hwn yn effeithio ar weithgareddau beunyddiol y rhai sy'n preswylio yn y tŷ, o ran eu cyfranogiad mewn gweithgareddau a hefyd ymddygiad problemus.

Sut y cysylltwyd â mi?
Rheolwr y Gwasanaeth Preswyl Cymunedol a roddodd ganiatâd inni gysylltu â chi, ac ef/hi a roddodd wybodaeth inni fel y gallem gysylltu â chi. Gan mai chi yw cynrychiolydd cyfreithiol y preswylydd yn y tŷ, hoffem ofyn ichi ystyried a fyddai cymryd rhan yn yr astudiaeth er pennaf les eich perthynas/cleient.

Beth fydd yn digwydd i'm perthynas/client os cydsyniad iddo/iddi gymryd rhan?
Bydd ymchwilydd yn ymweld â'r tŷ i arsylwi gweithgareddau beunyddiol y preswylwyr ar dri achlysur, sef unwaith cyn i'r staff dderbyn yr hyfforddiant rhyngweithiol ac unwaith eto fis ar ôl i'r hyfforddiant ddod i ben. Bydd y trydydd ymweliad yn digwydd ryw 6 mis ar ôl i'r staff gwblhau eu hyfforddiant. Bwriedir cynnal dau ymweliad â'r tŷ ar bob achlysur, a phob un yn para am deirawr. Bydd ymchwilwyr yn arsylwi'r

preswylwyr yn y fan a'r lle, gan nodi'r modd y maent yn cymryd rhan mewn gweithgareddau, yn rhyngweithio ag aelodau staff, ynghyd ag unrhyw ymddygiad problemus a fo ganddynt. Ar ben hynny, bydd ymchwilydd yn cyfarfod ag aelod o'r staff sy'n adnabod y preswylydd yn dda, er mwyn llenwi tair graddfa fesur yn ymwneud â galluoedd, medrau ac ymddygiad problemus y preswylydd. Trwy gydol yr astudiaeth, ni fydd yr ymchwilwyr yn rhyngweithio'n uniongyrchol â'r preswylwyr; bydd aelod o'r staff bob amser yn bresennol, ac ni fyddant yn arsylwi mewn mannau preifat, megis yr ystafell wely neu'r ystafell ymolchi.

A fydd cyfranogiad yn gyfrinachol?
Byddwn yn trin y wybodaeth a gasglwn trwy'r arsylwadau a'r graddfeydd mesur fel pe bai'n llwyr gyfrinachol. Er sicrhau bod y cyfranogwyr yn ddi-enw; caiff pob preswylydd god rhif, a fydd i'w weld ar unrhyw ffeiliau o hynny allan, fel na fydd data electronig na phrintiedig yn enwi preswylwyr na staff gofal. Byddwn yn cadw copïau caled y graddfeydd mesur a'r rhestr sy'n cysylltu enwau cyfranogwyr â'u rhifau cod yn ddiogel dan glo ym Mhrifysgol Cymru, Bangor, ac yn eu dinistrio ar ddiwedd yr astudiaeth. Cedwir ffeiliau data electronig, a fydd yn cynnwys gwybodaeth ddi-enw nad oes modd ei chysylltu â neb, am gyfnod amhenodol fel rhan o ymchwil gyfredol.

Beth fydd yn digwydd os nad wyf am i'm perthynas/cleient gymryd rhan?
Nid oes unrhyw reidrwydd arnoch i gydsynio i'ch perthynas/cleient gymryd rhan, ac mae gennych hawl i beidio. Os penderfynwch gydsynio ar ran eich perthynas/cleient, byddwch yn cadw'r daflen wybodaeth hon, a gofynnir ichi lofnodi ffurflen gydsynio – a chadw un copi ohoni. Os byddwch yn cydsynio, ond yn ail-feddwl ar unrhyw adeg yn ystod yr astudiaeth, mae gennych hawl i dynnu eich perthynas/cleient ôl o'r astudiaeth heb roi unrhyw reswm.

Sut y bydd yr astudiaeth hon o fudd i'm perthynas/cleient?
Os awgryma'r astudiaeth bresennol fod Cynhaliaeth Weithredol yn fuddiol i breswylwyr mewn tai, datblygir y rhaglen hon ymhellach i ateb anghenion y bobl sy'n byw yn y tai. Yn ôl nifer o astudiaethau a gynhaliwyd gan ymchwilwyr eraill, pan fo staff gofal yn derbyn hyfforddiant mewn Cynhaliaeth Weithredol, caiff preswylwyr nifer o fuddion uniongyrchol. Cymerant ran mewn mwy o weithgareddau o ddydd i ddydd, maent yn cymdeithasu ar raddfa fwy, a chânt gymorth mwy effeithiol gan y staff. Trwy hyn, bydd preswylwyr yn datblygu eu cymwyseddau, deuant yn fwy annibynnol, a gallant ddewis fel unigolion. Er enghraifft, yn ôl astudiaethau blaenorol, pan fydd Cynhaliaeth Weithredol wedi'i rhoi, mae'r amser y mae preswylwyr yn ei dreulio mewn gweithgaredd yn cynyddu ryw 20% (o ryw 30% i ryw 50%). Mewn diwrnod 16 awr, mae hyn yn cyfateb i fwy na 3 awr o weithgareddau, sy'n gynnydd sylweddol. Mae cynnydd mewn cysylltiad / gweithgaredd yn cyfrannu at ansawdd bywyd a lles corfforol.

Beth fydd yn digwydd os aiff rhywbeth o'i le yn ystod yr astudiaeth?
Hyd eithaf ein gwybodaeth, nid oedd unrhyw faterion perthnasol yn codi mewn astudiaethau blaenorol, ac nid ydym yn rhagweld unrhyw anawsterau. Bwriad y protocol wrth arsylwi yw lleihau anhwylustod i'r preswylwyr, a bydd yr ymchwilwyr yn ymweld â'r tai i ddod i adnabod y preswylwyr cyn i'r astudiaeth gychwyn. Bydd aelodau staff bob amser yn bresennol yn y tŷ pan fydd yr ymchwilwyr yno. Yn ogystal, arolygir yr ymchwilwyr gan arolygwyr academaidd sy'n brofiadol iawn ym maes

gweithio a gwneud ymchwil gydag oedolion sydd ag anabledd dysgu. Bydd yr arolygwyr hynny yn monitro gwaith yr ymchwilwyr yn wythnosol.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth hon?
Cyflwynir canlyniadau'r astudiaeth hon i gyfranogwyr fel grŵp, heb gyfeirio o gwbl at ddata unigolion. Lle bo hynny'n gymwys, cyflwynir y canlyniadau i reolwyr y Gwasanaeth Preswyl Cymunedol, i staff ac i gleientau. Bydd y canfyddiadau yn rhan o ddau gymhwyster addysgol: sef PhD ac MSc, y rhoddir copïau ohonynt yn Llyfrgell Prifysgol Cymru, Bangor. Ceir cyhoeddiadau hefyd mewn cylchgronau gwyddonol a chyflwyniadau mewn cynadleddau.

Pwy sydd wedi arolygu'r astudiaeth hon?
Mae'r astudiaeth wedi'i harolygu gan Bwyllgor Ymchwil Lleol Gogledd-Ddwyrain Cymru a chan Bwyllgor Moeseg yr Ysgol Seicoleg, Prifysgol Cymru, Bangor.

Pwy yw'r ymchwilwyr?
Dau ymchwilydd sy'n ymwneud â'r astudiaeth:
Vasiliki Totsika, Myfyrwraig PhD, a Jonathan McCarthy, Myfyriwr MSc. Mae'r ddau ymchwilydd yn astudio yn yr Ysgol Seicoleg, Prifysgol Cymru, Bangor.
Mae Jonathan yn Gynghorwr Ymddygiad a Vasiliki yn Gynorthwy-ydd Ymchwil er Anrhydedd yn y Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru.

Arolygir hwy gan:
– Yr Athro Richard Hastings, Athro Seicoleg a Dirprwy Bennaeth yr Ysgol Seicoleg, Prifysgol Cymru, Bangor
– Dr Sandy Toogood, Dadansoddwr Ymgynghorol Ymddygiad, Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru, ac Uwch Gymrawd Ymchwil, Ysgol Seicoleg, Prifysgol Cymru, Bangor
– Dr Carl Hughes, Cymrawd Dysgu, Ysgol Seicoleg, Prifysgol Cymru, Bangor

Cysylltiadau am fwy o wybodaeth:
Vasiliki Totsika, Ysgol Seicoleg, Prifysgol Cymru, Bangor
Adeilad Brigantia, Bangor Gwynedd LL57 2AS
Ffôn: 01248 351151 est.: 8706
E-bost: psp047@bangor.ac.uk

Jonathan McCarthy, Gwasanaethau Cynnal Dwys, Trinity House, Trinity Street, Wrecsam LL11 1NL
Ffôn: 01978 290020
E-bost: JONATHAN.MCCARTHY@new.tr-wales.nhs.uk

Os oes gennych unrhyw gŵynion ynglŷn â'r modd y gwneir yr ymchwil hon, cysylltwch â'r naill neu'r llall o'r bobl isod:

Dirprwy Pennaeth yr Ysgol Ysgol Seicoleg Prifysgol Cymru, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Prif Weithredwr Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru Ysbyty Wrecsam Maelor Ffordd Croesnewydd Wrecsam LL13 7TD

Diolch yn fawr iawn am ystyried cymryd rhan yn yr astudiaeth.

6.8a: Carer/Legal representative Cover Letter: Information of Participation-English

Carer/Legal Representative Information of Participation Cover Letter

Date: 12 May 2005
Version 1.1

Dear ,

We are currently carrying out a study on the quality of life of adults with a learning disability who live in residential accommodation. The focus of the study is on the way staff training impacts on the daily activities of residents and on their problem behaviour. This study is collaboration between the University of Wales, Bangor and Intensive Support Services, North East Wales NHS Trust.

We have invited to participate in the study and has given consent to participate. As the legal representative of we would like to inform you of his/her decision to participate in the study. Please find attached an information sheet that describes the study procedure in detail.

Yours Sincerely,

Vasiliki Totsika and Jonathan McCarthy

6.8b: Carer/Legal representative Cover Letter: Information of Participation-Welsh

Llythyr Ategol, er Gwybodaeth i Ofalwyr / Cynrychiolwyr Cyfreithiol, ynglŷn â Chyfranogiad

Dyddiad: 12 Mai 2005
Fersiwn 1.1

Annwyl ,

Rydym wrthi ar hyn o bryd yn cynnal astudiaeth ar ansawdd bywyd oedolion ag anabledd dysgu sy'n byw mewn cartrefi preswyl. Canolbwynt yr astudiaeth hon yw'r modd y mae'r hyfforddiant a gaiff y staff yn effeithio ar weithgareddau beunyddiol y preswylwyr ac ar eu hymddygiad problemus. Gwaith ar y cyd yw'r astudiaeth hon rhwng Prifysgol Cymru, Bangor a'r Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru.

Rydym wedi gwahodd i gymryd rhan yn yr astudiaeth, ac mae wedi cydsynio i cymryd rhan. Gan mai chi yw cynrychiolydd cyfreithiol , hoffem eich hysbysu ei b/fod wedi penderfynu cymryd rhan yn yr astudiaeth. Rydym yn amgáu taflen wybodaeth sy'n disgrifio trefn yr astudiaeth yn fanwl.

Yn gywir,

Vasiliki Totsika a Jonathan McCarthy

6.9a: Carer/Legal representative Information of Participation-English

Carer/Legal Representative Information of Participation

Date: 12 May 2005
Version: 1.1

The effects of Active Support Interactive Training in the daily activities of adults with a learning disability in residential services.

Your relative/client has consented to take part in a research study. As the legal representative it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and/or a relevant professional if you wish. Ask us if there is anything that is not clear or if you would like more information.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Health Research and You'. This leaflet gives more information about health research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW or online at www.ceres.org.uk/order.htm

What is the purpose of the study?
The aim of the study is to investigate the effects that staff training has on the quality of life of adults with a learning disability in residential settings. Care staff who work in the houses managed by Community Residential Services, North East Wales (NEW) NHS Trust, will receive interactive training on Active Support by Intensive Support Services NEW NHS, as part of their ongoing service development.

Our study is interested in seeing how this training impacts on the daily activities of the house residents in terms of their engagement in activities and problem behaviour.

How have I been contacted?
Permission to contact you was granted by the manager of Community Residential Service who provided us with your contact information. As the legal representative of the house resident, we are writing to inform you about he study your relative/client has consented to participate in.

What will happen to my relative/client during the study?
A researcher will visit the house to observe the daily activities of the residents on two occasions. Once before staff receive the interactive training and once again a month after the training ends. Two house visits are scheduled for every occasion, each of which will last three hours. Researchers will conduct real-time observations of residents' engagement in activities, their interactions with staff members and their problem behaviour. In addition, a researcher will meet with a member of staff, who knows the resident well, in order to fill in three rating scales related to the resident's ability skills and problem behaviour. Throughout the study researchers will not interact directly with the residents, there will always be a member of staff present and observations will not take place in private places, such as the bedrooms or the bathroom.

Will participation be confidential?
Information gathered through the observations and the rating scales will be treated with the strictest confidence. In order to ensure anonymity, each resident will be assigned a number code which will appear on any files thereafter, so that electronic or hard copy data do not identify residents or care staff. The hard copies of the rating scales and the list that links residents' names to their number codes will be kept locked safely in the University of Wales, Bangor and will be destroyed at the end of the study. Electronic data files which will contain anonymous, non-identifiable information will be kept indefinitely as part of ongoing research.

What if my relative/client changes their mind?
Participation in this study is entirely voluntary. Your relative/client has consented independently to participate and has been informed that if at any point during the study changes their mind, they are free to withdraw without giving us a reason.

How will this study benefit my relative/client?
If the present study suggests that Active Support benefits house residents then this programme will be further developed to suit the needs of the people living in the houses. A number of studies conducted by other researchers suggest that when care staff receive training on Active Support, there are a number of direct benefits for residents. They participate in more activities on a daily basis, they have more social interactions and they receive more efficient support and assistance from staff. In this way, residents develop their competencies, become more autonomous and can exercise individual choice. As an example, previous studies have found that after Active Support the amount of time residents spend engaged in an activity increases by about 20% (from about 30% to 50% approx). In a 16-hr day this is equivalent to more than 3 hours of doing things, which is a substantial increase. Increased engagement/activity contributes to quality of life and physical well-being.

What if something goes wrong during the study?
To the best of our knowledge, there were no issues arising in previous studies and we do not anticipate any difficulties. The observational protocol has been designed to minimise inconvenience to the residents and the researchers will visit the houses to familiarise with the residents before the study begins. Members of staff will always be present in the house when researchers are there. In addition, researchers are supervised by academic supervisors who are highly experienced in working and doing research with adults with a learning disability. Researchers' work will be monitored weekly by their supervisors.

What will happen with the results of this study?
The results of this study will be presented for participants as a group and no mention to individuals' data will take place. The results will be presented to Community Residential Service managers, staff and clients, where applicable. Findings will form part of two educational qualifications: a PhD and a MSc, copies of which will be given to the Library of the University of Wales, Bangor. Publications in scientific journals and presentations in conferences will also be given.

Who has reviewed this study?
The project has been reviewed by North East Wales Local Research Committee and by the Ethics Committee of the School of Psychology, University of Wales, Bangor.

Who are the researchers?
There are two researchers involved in the study:
Vasiliki Totsika, PhD Student, and Jonathan McCarthy, MSc Student. Both researchers study at the School of Psychology, University of Wales, Bangor.
Jonathan is a Behavioural Advisor and Vasiliki is an Honorary Research Assistant at Intensive Support Services, North East Wales, NHS trust.

They are supervised by:
- Prof. Richard Hastings, Professor of Psychology and Deputy Head of School of Psychology, University of Wales, Bangor
- Dr Sandy Toogood, Consultant Behaviour Analyst, Intensive Support Services, North East Wales NHS, and Senior Research Fellow, School of Psychology, University of Wales, Bangor
- Dr Carl Hughes, Teaching Fellow, School of Psychology, University of Wales, Bangor

Contacts for further information:
Vasiliki Totsika, School of Psychology, University of Wales, Bangor
Adeilad Brigantia,Bangor, Gwynedd LL57 2AS
Tel: 01248 351151 ext.: 8706
Email: psp047@bangor.ac.uk

Jonathan McCarthy, Intensive Support Services, Trinity House, Trinity Road Wrexham LL11 1NL
Tel: 01978 290020
Email: JONATHAN.MCCARTHY@new.tr-wales.nhs.uk

If you have any complaints about how this study is conducted please address these to either of the persons below:

Professor Fergus Lowe Head of School School of Psychology University of Wales, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Chief Executive North East Wales NHS Trust Wrexham Maelor Hospital Croesnewydd Road Wrexham, LL13 7TD

Thank you very much for taking the time to read this.

6.9b: Carer/Legal representative Information of Participation-Welsh

Taflen Wybodaeth i Ofalwyr / Cynrychiolwyr Cyfreithiol ynglŷn â Chyfranogiad

Dyddiad: 12 Mai 2005
Fersiwn: 1.1

Effeithiau Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol ar weithgareddau beunyddiol oedolion ag anabledd dysgu mewn gwasanaethau preswyl.

Mae eich perthynas/cleient wedi cydsynio i gymryd rhan mewn astudiaeth ymchwil. Gan mai chi yw ei g/chynrychiolydd cyfreithiol, mae'n bwysig eich bod yn deall y rheswm am wneud yr ymchwil a'r hyn y bydd yn ei olygu. Cymerwch amser i ddarllen y wybodaeth isod yn ofalus a'i thrafod â ffrindiau, perthnasau a/neu â gweithiwr proffesiynol perthnasol os dymunwch. Holwch ni os ydych yn ansicr ynglŷn â rhywbeth, neu os hoffech gael mwy o wybodaeth.

Mae Consumers for Ethics in Research (CERES) wedi cyhoeddi taflen yn dwyn y teitl 'Health Research and You'. Mae'r daflen hon yn rhoi mwy o wybodaeth ynglŷn ag ymchwil iechyd ac yn edrych ar rai cwestiynau y gallech fod yn awyddus i'w gofyn. Cewch gopi gan CERES, PO Box 1365, Llundain N16 0BW neu ar-lein ar www.ceres.org.uk/order.htm

Beth yw diben yr astudiaeth?
Amcan yr astudiaeth yw ymchwilio i'r effeithiau a gaiff hyfforddiant staff ar ansawdd bywyd oedolion ag anabledd dysgu mewn cartrefi preswyl. Bydd staff gofal sy'n gweithio yn y tai a reolir gan Wasanaethau Preswyl Cymunedol, Ymddiriedolaeth Iechyd Gogledd-Ddwyrain Cymru yn derbyn hyfforddiant rhyngweithiol ar Gynhaliaeth Weithredol trwy Wasanaethau Cynnal Dwys yr Ymddiriedolaeth honno, a hynny fel rhan o'u datblygiad proffesiynol parhaus.

Wrth inni gynnal yr astudiaeth hon, mae gennym ddiddordeb mewn canfod sut y mae'r hyfforddiant hwn yn effeithio ar weithgareddau beunyddiol y rhai sy'n preswylio yn y tŷ, o ran eu cyfranogiad mewn gweithgareddau a hefyd ymddygiad problemus.

Sut y cysylltwyd â mi?
Rheolwr y Gwasanaeth Preswyl Cymunedol a roddodd ganiatâd inni gysylltu â chi, ac ef/hi a roddodd wybodaeth inni fel y gallem gysylltu â chi. Gan mai chi yw cynrychiolydd cyfreithiol y preswylydd yn y tŷ, rydym yn ysgrifennu i'ch hysbysu am yr astudiaeth y mae eich perthynas/cleient wedi cydsynio i gymryd rhan ynddi.

Beth fydd yn digwydd i'm perthynas/cleient yn ystod yr astudiaeth?
Bydd ymchwilydd yn ymweld â'r tŷ i arsylwi gweithgareddau beunyddiol y preswylwyr ar ddau achlysur, sef. unwaith cyn i'r staff dderbyn yr hyfforddiant rhyngweithiol ac unwaith eto fis ar ôl i'r hyfforddiant ddod i ben. Bwriedir cynnal dau ymweliad â'r tŷ ar bob achlysur, a phob un yn para am deirawr. Bydd ymchwilwyr yn arsylwi'r preswylwyr yn y fan a'r lle, gan nodi'r modd y maent yn cymryd rhan mewn gweithgareddau, yn rhyngweithio ag aelodau staff, ynghyd ag unrhyw ymddygiad

problemus a fo ganddynt. Ar ben hynny, bydd ymchwilydd yn cyfarfod ag aelod o'r staff sy'n adnabod y preswylydd yn dda, er mwyn llenwi tair graddfa fesur yn ymwneud â galluoedd, medrau ac ymddygiad problemus y preswylydd. Trwy gydol yr astudiaeth, ni fydd yr ymchwilwyr yn rhyngweithio'n uniongyrchol â'r preswylwyr; bydd aelod o'r staff bob amser yn bresennol, ac ni fyddant yn arsylwi mewn mannau preifat, megis yr ystafell wely neu'r ystafell ymolchi.

A fydd cyfranogiad yn gyfrinachol?
Byddwn yn trin y wybodaeth a gasglwn trwy'r arsylwadau a'r graddfeydd mesur fel pe bai'n llwyr gyfrinachol. Er sicrhau bod y cyfranogwyr yn ddi-enw; caiff pob preswylydd god rhif, a fydd i'w weld ar unrhyw ffeiliau o hynny allan, fel na fydd data electronig na phrintiedig yn enwi preswylwyr na staff gofal. Byddwn yn cadw copïau caled y graddfeydd mesur a'r rhestr sy'n cysylltu enwau cyfranogwyr â'u rhifau cod yn ddiogel dan glo ym Mhrifysgol Cymru, Bangor, ac yn eu dinistrio ar ddiwedd yr astudiaeth. Cedwir ffeiliau data electronig, a fydd yn cynnwys gwybodaeth ddi-enw nad oes modd ei chysylltu â neb, am gyfnod amhenodol fel rhan o ymchwil gyfredol.

Beth fydd yn digwydd os bydd fy mherthynas / fy nghleient yn ail-feddwl?
Mae cymryd rhan yn yr astudiaeth hon yn llwyr wirfoddol. Mae eich perthynas/cleient wedi cydsynio'n annibynnol i gymryd rhan, ac wedi cael gwybod fod ganddo/ganddi berffaith hawl i dynnu'n ôl heb roi unrhyw reswm inni os bydd ef/hi'n ail-feddwl ar unrhyw adeg yn ystod yr astudiaeth.

Sut y bydd yr astudiaeth hon o fudd i'm perthynas/cleient?
Os awgryma'r astudiaeth bresennol fod Cynhaliaeth Weithredol yn fuddiol i breswylwyr mewn tai, datblygir y rhaglen hon ymhellach i ateb anghenion y bobl sy'n byw yn y tai. Yn ôl nifer o astudiaethau a gynhaliwyd gan ymchwilwyr eraill, pan fo staff gofal yn derbyn hyfforddiant mewn Cynhaliaeth Weithredol, caiff preswylwyr nifer o fuddion uniongyrchol. Cymerant ran mewn mwy o weithgareddau o ddydd i ddydd, maent yn cymdeithasu ar raddfa fwy, a chânt gymorth mwy effeithiol gan y staff. Trwy hyn, bydd preswylwyr yn datblygu eu cymwyseddau, deuant yn fwy annibynnol, a gallant ddewis fel unigolion. Er enghraifft, yn ôl astudiaethau blaenorol, pan fydd Cynhaliaeth Weithredol wedi'i rhoi, mae'r amser y mae preswylwyr yn ei dreulio mewn gweithgaredd yn cynyddu ryw 20% (o ryw 30% i ryw 50%). Mewn diwrnod 16 awr, mae hyn yn cyfateb i fwy na 3 awr o weithgareddau, sy'n gynnydd sylweddol. Mae cynnydd mewn cysylltiad / gweithgaredd yn cyfrannu at ansawdd bywyd a lles corfforol.

Beth fydd yn digwydd os aiff rhywbeth o'i le yn ystod yr astudiaeth?
Hyd eithaf ein gwybodaeth, nid oedd unrhyw faterion perthnasol yn codi mewn astudiaethau blaenorol, ac nid ydym yn rhagweld unrhyw anawsterau. Bwriad y protocol wrth arsylwi yw lleihau anhwylustod i'r preswylwyr, a bydd yr ymchwilwyr yn ymweld â'r tai i ddod i adnabod y preswylwyr cyn i'r astudiaeth gychwyn. Bydd aelodau staff bob amser yn bresennol yn y tŷ pan fydd yr ymchwilwyr yno. Yn ogystal, arolygir yr ymchwilwyr gan arolygwyr academaidd sy'n brofiadol iawn ym maes gweithio a gwneud ymchwil gydag oedolion sydd ag anabledd dysgu. Bydd yr arolygwyr hynny yn monitro gwaith yr ymchwilwyr yn wythnosol.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth hon?
Cyflwynir canlyniadau'r astudiaeth hon i gyfranogwyr fel grŵp, heb gyfeirio o gwbl at ddata unigolion. Lle bo hynny'n gymwys, cyflwynir y canlyniadau i reolwyr y Gwasanaeth Preswyl Cymunedol, i staff ac i gleientau. Bydd y canfyddiadau yn rhan o ddau gymhwyster addysgol: sef PhD ac MSc, y rhoddir copïau ohonynt yn Llyfrgell Prifysgol Cymru, Bangor. Ceir cyhoeddiadau hefyd mewn cylchgronau gwyddonol a chyflwyniadau mewn cynadleddau.

Pwy sydd wedi arolygu'r astudiaeth hon?
Mae'r astudiaeth wedi'i harolygu gan Bwyllgor Ymchwil Lleol Gogledd-Ddwyrain Cymru a chan Bwyllgor Moeseg yr Ysgol Seicoleg, Prifysgol Cymru, Bangor.

Pwy yw'r Ymchwilwyr?
Dau ymchwilydd sy'n ymwneud â'r astudiaeth:
Vasiliki Totsika, Myfyrwraig PhD, a Jonathan McCarthy, Myfyriwr MSc. Mae'r ddau ymchwilydd yn astudio yn yr Ysgol Seicoleg, Prifysgol Cymru, Bangor.
Mae Jonathan yn Gynghorwr Ymddygiad a Vasiliki yn Gynorthwy-ydd Ymchwil er Anrhydedd yn y Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru.

Arolygir hwy gan:
– Yr Athro Richard Hastings, Athro Seicoleg a Dirprwy Bennaeth yr Ysgol Seicoleg, Prifysgol Cymru, Bangor
– Dr Sandy Toogood, Dadansoddwr Ymgynghorol Ymddygiad, Gwasanaethau Cynnal Dwys, Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru, ac Uwch Gymrawd Ymchwil, Ysgol Seicoleg, Prifysgol Cymru, Bangor
– Dr Carl Hughes, Cymrawd Dysgu, Ysgol Seicoleg, Prifysgol Cymru, Bangor

Cysylltiadau am fwy o wybodaeth:
Vasiliki Totsika, Ysgol Seicoleg, Prifysgol Cymru, Bangor
Adeilad Brigantia, Bangor Gwynedd LL57 2AS
Ffôn: 01248 351151 est.: 8706
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Jonathan McCarthy, Gwasanaethau Cynnal Dwys, Trinity House, Trinity Street, Wrecsam LL11 1NL
Ffôn: 01978 290020
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Os oes gennych unrhyw gŵynion ynglŷn â'r modd y gwneir yr ymchwil hon, cysylltwch â'r naill neu'r llall o'r bobl isod:

Yr Athro Fergus Lowe Pennaeth yr Ysgol Ysgol Seicoleg Prifysgol Cymru, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Prif Weithredwr Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru Ysbyty Wrecsam Maelor Ffordd Croesnewydd Wrecsam LL13 7TD

Diolch yn fawr am roi o'ch amser i ddarllen hyn.

6.10a: Carer Information Sheet-English

Carer Information Sheet

Date: 21 June 2005
Version: 1.3

The effects of Active Support Interactive Training in the daily activities of adults with a learning disability in residential services.

Your client is being invited to take part in a research study. Please take time to read the following information and contact us if you feel that something is unclear or you would like more information.

What is the study about?
This is a study looking into what happens to house residents when care staff in Community Residential Service participate in Active Support Interactive training that Intensive Support Services (ISS) are conducting. Your manager has already informed you of the Active Support Interactive training that is going to take place during the summer. You can find more information on this by conducting your manager who has been given by ISS a related document entitled: "Active Support Interactive Training: Research Opportunity". This study is going to look how the daily activities of residents change and how their problem behaviour is affected after Intensive Support Services conduct the training.

How have I been conducted?
First permission to approach care staff was granted by the manager of your service. Managers have been informed of the study and they will have provided contact details.

What is going to happen?
There are two researchers who are going to do observations of the residents and their interaction with staff members in the houses. Two visits for observations are scheduled before Active Support training, two visits after Active Support training and another two a few months after the training (around March 2005). Each visit is scheduled to last three hours (from 16:00 to 19:00 in the afternoon).The researchers will contact you to arrange the observation dates at times that best suit your and your colleagues' work schedule in the house.

We would also like some information on participants' ability skills and challenging behaviour. For this, we would like to meet one member of staff from the house, who knows the participant well, at a time and place of their convenience (before Active Support training). At this meeting there are three rating scales for each participant to be filled in and the whole thing is expected to last about half an hour. We would also like to meet with you shortly after Active Support in order to fill in one of the rating scales that you will have filled in before the training.

Information collected will be treated in the strictest confidence. All data will be anonymous; each resident will be allocated a number code so that all information from the databases will not identify residents or members of staff. All the hard copies of the rating scales and the list that links participants' names to code numbers will be destroyed at the end of the study. The electronic databases with the non-identifiable data will be kept indefinitely as part of ongoing studies.

What if I don't want to meet with the researchers?
You are under no obligation to help us with this and you are free to choose not to. Not every member of staff in the houses needs to meet with the researchers. We only need to meet with care staff who know the participant well and would be happy to fill in the rating scales. If you decide to support us and then change your mind, just let us know that you are not available to be contacted any more and you do not have to give us a reason.

What if I have concerns?
For any concerns you may have or for further information please contact:

Jonathan McCarthy, Intensive Support Services, Trinity House, Trinity Street,
Wrexham LL11 1NL
Tel: 01978 290020
Email: JONATHAN.MCCARTHY@new-tr.wales.nhs.uk

Vasiliki Totsika, School of Psychology, University of Wales, Bangor
Adeilad Brigantia, Bangor Gwynedd LL57 2AS
Tel: 01248 351151
Email: psp047@bangor.ac.uk

If you have any complaints about how this study is conducted please address these to either of the persons below:

Deputy Head of School School of Psychology University of Wales, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Chief Executive North East Wales NHS Trust Wrexham Maelor Hospital Croesnewydd Road Wrexham, LL13 7TD

Thank you for taking the time to read this.

6.10b: Carer Information Sheet-Welsh

Taflen Wybodaeth i Ofalwyr

Dyddiad: 21 Mehefin 2005
Fersiwn: 1.3

Effeithiau Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol ar weithgareddau beunyddiol oedolion ag anabledd dysgu mewn gwasanaethau preswyl.

Mae gwahoddiad i'ch cleient gymryd rhan mewn astudiaeth ymchwil. Cymerwch eich amser i ddarllen y wybodaeth isod a chysylltwch â ni os ydych yn ansicr ynglŷn â rhywbeth, neu os hoffech gael mwy o wybodaeth.

Beth yw pwnc yr astudiaeth?
Astudiaeth yw hon sy'n edrych ar yr hyn sy'n digwydd i breswylwyr tai pan fydd staff gofalu mewn Gwasanaethau Preswyl Cymunedol yn cymryd rhan yn yr Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol a gynhelir gan y Gwasanaethau Cynnal Dwys (GCD). Mae eich rheolwr eisoes wedi rhoi gwybod ichi am yr Hyfforddiant Rhyngweithiol mewn Cynhaliaeth Weithredol sydd i'w gynnal yn yr haf. Cewch fwy o wybodaeth am hyn trwy gysylltu â'ch rheolwr, sydd wedi derbyn dogfen berthnasol gan GCD, yn dwyn y teitl: "Active Support Interactive Training: Research Opportunity": Mae'r astudiaeth hon yn mynd i edrych ar y modd y mae gweithgareddau beunyddiol preswylwyr yn newid a'r newid a fo yn eu hymddygiad ar ôl i'r Gwasanaethau Cynnal Dwys gynnal yr hyfforddiant.

Sut y cysylltwyd â mi?
Yn gyntaf, rheolwr eich gwasanaeth a roddodd ganiatâd inni gysylltu â staff gofal. Mae'r rheolwyr wedi cael gwybod am yr astudiaeth, a byddant wedi rhoi manylion cyswllt.

Beth sy'n mynd i ddigwydd?
Mae dau ymchwilydd yn mynd i arsylwi'r preswylwyr a'r modd y maent yn rhyngweithio ag aelodau staff yn y tai. Mae dau ymweliad arsylwi i'w cynnal cyn yr hyfforddiant mewn Cefnogaeth Weithredol, dau ymweliad ar ôl yr hyfforddiant, ac un arall rai misoedd wedi'r hyfforddiant (tua Mawrth 2005). Bwriedir i bob ymweliad gymryd 3 awr (o 16:00 tan 19:00 yn y prynhawn). Bydd yr ymchwilwyr yn cysylltu â chi i drefnu y dyddiadau a'r amseroedd arsylwi sydd fwyaf hwylus o ran eich cynlluniau gwaith chi a'ch cydweithwyr yn y tŷ.

Hoffem hefyd gael rhywfaint o wybodaeth ynglŷn â gallu, medrau ac ymddygiad heriol y cyfranogwyr. Ar gyfer hynny, hoffem gyfarfod ag un aelod o staff y tŷ sy'n adnabod y cyfranogwr yn dda, ar adeg ac mewn man sy'n hwylus iddynt (cyn yr hyfforddiant mewn Cynhaliaeth Weithredol). Yn y cyfarfod hwn, ceir tair graddfa fesur i'w llenwi yn achos pob cyfranogwr, a disgwylir i'r cyfan gymryd rhyw hanner awr. Hoffem hefyd gyfarfod â chi yn fuan ar ôl y Gefnogaeth Weithredol, er mwyn llenwi un o'r graddegau mesur y byddwch wedi'u llenwi cyn yr hyfforddiant.

Bydd yr holl wybodaeth a gasglwn yn llwyr gyfrinachol. Bydd yr holl ddata yn ddi-enw; caiff pob preswylydd gôd rhif, fel na fydd modd defnyddio unrhyw wybodaeth o'r gronfa ddata i enwi preswylwyr na staff. Byddwn yn dinistrio holl gopïau caled y graddfeydd mesur a'r rhestr sy'n cysylltu enwau cyfranogwyr â rhifau côd ar ddiwedd yr astudiaeth. Cedwir y cronfeydd data electronig â'r data di-enw am gyfnod amhenodol fel rhan o'r astudiaethau cyfredol.

Beth fydd yn digwydd os na fyddaf am gyfarfod â'r ymchwilwyr?
Nid oes unrhyw reidrwydd arnoch i'n cynorthwyo yn hyn o beth, ac mae gennych hawl i beidio. Nid oes angen i'r holl staff gyfarfod â'r ymchwilwyr. Yr unig staff gofal y mae angen inni gyfarfod â hwy yw'r rhai sy'n adnabod y cyfranogwr yn dda ac a fyddai'n fodlon llenwi'r graddegau mesur. Os penderfynwch ein cynorthwyo, ac wedyn ail-feddwl, rhowch wybod inni na fyddwch ar gael mwyach inni gysylltu â chi – nid oes raid ichi roi rheswm inni.

Beth os bydd gennyf bryderon?
Os oes gennych unrhyw bryderon, neu am fwy o wybodaeth, cysylltwch â:

Jonathan McCarthy, Gwasanaethau Cynnal Dwys, Trinity House, Trinity Street, Wrecsam LL11 1NL
Ffôn: 01978 290020
E-bost: JONATHAN.MCCARTHY@new-tr.wales.nhs.uk

Vasiliki Totsika, Ysgol Seicoleg, Prifysgol Cymru, Bangor
Adeilad Brigantia, Bangor Gwynedd LL57 2AS
Ffôn: 01248 351151
E-bost: psp047@bangor.ac.uk

Os oes gennych unrhyw gŵynion ynglŷn â'r modd y gwneir yr ymchwil hon, cysylltwch â'r naill neu'r llall o'r bobl isod:

Dirprwy Pennaeth yr Ysgol Ysgol Seicoleg Prifysgol Cymru, Bangor Adeilad Brigantia Bangor, Gwynedd LL57 2AS	Hilary Peplar Prif Weithredwr Ymddiriedolaeth GIG Gogledd-Ddwyrain Cymru Ysbyty Wrecsam Maelor Ffordd Croesnewydd Wrecsam LL13 7TD

Diolch am roi o'ch amser i ddarllen hyn.

Appendix 7: Interview Schedule for staff who participated in Interactive Training (IT) for Active Support (AS) (Chapter 5)

A. Rational/Need for AS training:

- Why do you think the service decided to adopt AS as a mechanism to support the service users?
  (prompt: In your opinion, what can AS model offer to the services users?)

B. Delivery of training:

The Behavioural Support Team recently completed training 58 support staff in the CRS projects.

(Note: For Support Staff who work in more than one projects, we prompt them to base their answers on the project in which they received their IT training (or work most hours if they have since moved projects)

- How do you think the IT went?

1. Thinking about *your* training experience:

- What was good about your training? Can you give some examples of things that went *well during* your training?
- What was not so good about your training? Can you give some examples of things that did *not* go so well *during* your training?

C. Thinking in general about Interactive training as the type of training that happens in the house and involves a member of staff working in real time with a resident with the focus on one-to-one interaction:

- What would you say are the factors that make this type of training helpful?
- What are some of the difficulties about this type of training?

3. If you were going to do IT again:

- Can you name two (or more) things that you would keep the same?
- Can you name two (or more) things that you would change?

C. Implementation of training:

Following the training:

- Is there something that you do differently in your everyday work as a result of the training? Can you give some examples?
- These things that you just mentioned (or repeat the examples given), why was it easy to use them?
  (prompt: What is it about _____ and/or _____ that has helped you put them in practice?)
- Is there anything that you learned during IT that you haven't actually used in your everyday work? Can you give some examples?
- These things that you just mentioned (or repeat the examples given), why is it harder to use them?
  (prompt: What are the things that make it difficult to take what you learned during the training and use it in your everyday work?)

D. Implementation of AS:

With the end of IT across all CRS projects, the training cycle on AS has been completed (workshops and IT).

- Did you participate in the AS workshops?
- Can you identify some of the things from AS that are used in your projects?

- (prompt: things like activity schedules)
- How easy is it to use these (name examples) in the daily running of the house?
- Can you identify some of AS things that you do not use in your project?
- What are the factors that do not allow you to include these (name examples) in the project?

One last question: How long have you been working in Community Residential Service:

E. End:

- Is there something you would like to add?

Thank you!