

Title page

Full title:

## **Engagement in meaningful activity and ‘active support’ of people with intellectual disabilities in residential care**

Running title:

**Engagement and ‘active support’**

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**Abstract**

Forty-nine adults with learning disabilities living in 13 small staffed homes in England were studied as part of larger projects in 1997 and again in 2000. A pre-test/post-test comparison group design was used to assess differences in staff implementation of 'active support', service user engagement in meaningful activities and adaptive behaviour. Homes which adopted active support showed significantly increased engagement in meaningful activity and adaptive behaviour between 1997 and 2000. A comparison group showed no significant change.

## Introduction

As Bellamy, Newton, LeBaron, & Horner (1990) have argued, the purpose of services for people with intellectual disabilities is to improve people's lives. Not just to provide richer and more stimulating environments (improve service capacity), nor to increase scores on, for example, measures of individual development (improve individual progress), but to translate these changes into improvement in how people live their lives day by day. Unfortunately, there is considerable evidence that the developmental gains commonly reported after transfer from institutions to homes in the community (Cambridge, Hayes, Knapp, Gould, & Fenyo, 1994; Conroy, 1996; Conroy, Efthimiou, & Lemanowicz, 1982) have not always been matched by improvements in the extent to which residents take part in everyday activities. In many community services, as in institutions, people with intellectual disabilities spend large amounts of time literally doing nothing (Bratt & Johnson, 1988; Emerson & Hatton, 1996; Mansell, 1996).

Inactivity, boredom and isolation in residential care of people with intellectual disabilities substantially reflects the performance of staff (Landesman-Dwyer, Sackett, & Kleinman, 1980; Rice & Rosen, 1991). Staff mediate access to, and use of, the opportunities presented by the home and community through the way they provide help and encouragement. They control access to many materials and activities, eg by setting out and preparing materials so that residents can take part in activity. They make it more or less likely that clients will experience the reinforcement intrinsic to the task by the level of assistance they provide, and they shape client behaviour by their own feedback and reinforcement. They reinforce either client engagement in meaningful activity or passivity and inactivity through the disposition of their social interaction.

A number of studies have shown that even very severely or profoundly disabled residents can significantly increase the extent to which they participate in meaningful activities if staff adopt what has come to be called an 'active support' model of care (Brown, Toogood, & Brown, 1987; Felce, de Kock, & Repp, 1986; Felce & Perry, 1995; Jones et al., 1999; Mansell, 1994, 1995). Active support (Jones et al., 1996; Mansell, 1998; Mansell, Hughes, & McGill, 1994) was based on approaches described by Mansell *et al* (Mansell, Felce, Jenkins, de Kock, & Toogood, 1987; Mansell, Jenkins, Felce, & de Kock, 1984) and Felce (Felce, 1988). In general, 'active support' has four components:

1. service users are offered opportunities to take part in everyday activities at home and in the community, rather than childish or special therapeutic activities. The advantages of using real activities are (i) there is much more variety, (ii) many service users find them more interesting, (iii) they are less dependent on staff to signal each step and (iv) they provide opportunities for service users to show that they can take part successfully in ordinary activities like other people (Felce, de Kock, Mansell, & Jenkins, 1984; Mansell, Felce, de Kock, & Jenkins, 1982)

2. staff pay particular attention to working as a team and to scheduling and co-ordinating the choices and opportunities they offer. This involves establishing routines (like those found in everyone's lives) for the carrying out of ordinary activities (Saunders & Spradlin, 1991) and regular (on a shift or daily basis) planning of how they will systematically share themselves across clients to provide the high level of support needed, often by more than one person at a time, for meaningful participation
3. staff focus on helping service users take part minute-by-minute ('every moment has potential'), finding the parts of complicated tasks that even the most disabled person can do and doing the other parts of the task themselves, so that the person is almost guaranteed to succeed. Staff provide graded levels of assistance to ensure success and take account of individual preferences for activities and types of help to reduce the likelihood of challenging behaviour (Dyer, Dunlap, & Winterling, 1990)
4. staff carefully monitor, using simple record-keeping procedures, the degree to which service users are taking part in ordinary activities with the right level and kind of support. Regular, client-centred staff meetings allow for plans to be modified in the light of experience and support consistent practices across the staff group.

Active support is therefore an approach that consistently and frequently offers service users opportunities to take part in age-appropriate activities at home and in the community, building on and extending their skills and preferences. It shifts the focus of direct-care staff work from traditional caretaking or programmatic tasks to being accountable for the extent to which service users are involved in directing and carrying out the tasks of their everyday lives.

Although active support has been demonstrated to be a powerful technique for improving the quality of residents' lives (Felce et al., 2000; Jones et al., 1999), it has yet to have much impact beyond special demonstration projects. Typical staff performance in community services is still characterised by low levels of staff:client interaction (Emerson & Hatton, 1996) and little direct facilitation of resident participation (Emerson et al., 1999).

This study concerns the introduction of active support in residential services provided by a charity. It reports a natural experiment. In 1997, a research project collected information on approximately 25% of services provided by this charity and their residents. At this time, the charity was just beginning to adopt a policy of active support. In 2000, comparable information was collected on all the services and residents in order to review the needs and characteristics of people served and the kind of services they received. It was therefore possible to examine progress over time.

## **Method**

### **Design**

The design was a 'natural experiment', in which data collected in two larger studies was used to construct a non-equivalent pre-test/post-test comparison group study (Campbell & Stanley, 1963). Data was collected on participants at T1 (in 1997) and T2 (2000). At T1, 26 people lived in homes which had not yet begun to implement active support (the comparison group) and 23 people lived in four homes that had just begun its implementation (the experimental group). At T2, the same participants were visited again and, where possible, the same measures collected.

### **Participants**

Participants were 49 people with intellectual disabilities living in 13 small homes provided across England by a national charity. At T1, information was collected on their adaptive and maladaptive behaviour using the Behavior Development Survey (Conroy et al., 1982) (see below); on their age, gender and ethnicity; and on number of staff and residents in each house. Table 1 presents this information: there were no significant differences between the experimental and comparison groups at T1.

Table 1 about here

### **Measurement**

#### **Adaptive behaviour**

Adaptive behaviour of participants at T1 was rated using the Behavior Development Survey (BDS) (Conroy et al., 1982); this is a short form of the American Association on Mental Retardation Adaptive Behavior Scale (ABS) (Nihira, Foster, Shellhaas, & Leland, 1974). At T2, the BDS was calculated from ratings made using the full ABS (Nihira, Leland, & Lambert, 1993). In each home, these assessments were made by a member of staff who knew the individual resident well. Questions and clarification about the information required were dealt with by the second (T1) and fourth (T2) authors, who also followed up data collection to obtain the fullest information possible and dealt with queries arising during data processing. Inter-rater reliability was measured at T2 in the study from which these data are drawn, by having the same staff repeat the rating a few weeks after data collection. Pairs of ratings were made for 19 residents. Item-by-item agreement was calculated for each pair of ratings (Barlow & Hersen, 1984); agreement was scored when the two raters scored the item within a difference of one. Agreement averaged 96% (range 85-100).

#### **Active support**

Each home was visited at T1 and T2 in order to observe the way staff provided support to residents. Observations were made over a 3-4 hour period around a meal time because this seemed likely to provide many opportunities to see staff providing support. For each resident, the nature and quality of staff support was rated for the whole session using a 15-item rating scale, the Active Support

Measure (ASM) (Mansell & Elliott, 1996). Each item is scored on a scale of 0 (very poor performance, eg because no activities provided), through 1 (weak, inconsistent performance), 2 (mixed performance) to 3 (good, consistent performance), yielding a range of total scores from 0 to 45. The items are:

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 coordinated team to support clients
14. Teaching embedded in everyday activities
15. Specific, written individual programmes in routine use

Inter-rater reliability was assessed by having a second rater make independent assessments for 13 residents in the larger studies at T1 and 38 residents at T2. Total ASM scores made by each observer were highly correlated at T1 ( $\rho=0.96$ ,  $p<.001$ ) and T2 ( $\rho=0.98$ ,  $p<.001$ ).

### Engagement

At the same time that ratings of active support were made, researchers rated the engagement in meaningful activity of residents in each home using a similar four-point scale (0=largely disengaged, 1=engaged less than 50% time, 2=engaged between 50 and 75% time and 3=engaged more than 75% time). Inter-rater reliability was assessed using Cohen's kappa (Cohen, 1960) for 21 residents at T1 and 38 residents at T2. Kappa was 0.547 at T1 ( $p<.001$ ) and 0.953 at T2 ( $p<.001$ ).

### Analysis

Comparisons between experimental and comparison groups were made using independent-samples t-tests or Mann-Whitney *U*. Matched-pairs comparisons between T1 and T2 data was carried out using Wilcoxon's *Z*. All analyses were conducted using Version 10 of the Statistical Package for the Social Sciences (SPSS Inc, 2000).

### Results

Mean scores of the experimental and comparison groups at T1 and T2 are presented in Figure 1 (active support), Figure 2 (engagement) and Figure 3 (adaptive behavior). In each case, scores are presented as percentages of the maximum possible.

At T2, the comparison group score on the ASM had decreased slightly but this was not statistically significant ( $Z=-.346$ , n.s.). The experimental group had significantly increased their implementation of active support from 50% to 66% of the maximum possible ( $Z=-3.317$ ,  $p<.01$ ). The difference between experimental and comparison groups at T2 was significant ( $U=76$ ,  $Z=-2.166$ ,  $p<.05$ ).

The comparison group score for engagement at T2 increased from 7% to 20%, but this was not significant ( $Z=-1.667$ , n.s.). The experimental group had significantly increased mean engagement of service users in meaningful activity from 7% to 33% ( $Z=-3.557$ ,  $p<.001$ ). The difference between experimental and comparison groups at T2 was not significant ( $U=236.5$ ,  $Z=-1.253$ , n.s.).

In terms of change in adaptive behaviour, the comparison group score at T2 increased significantly from 30% to 35% of the maximum score ( $Z=-2.069$ ,  $p<.05$ ). The experimental group also significantly increased independence of service users ( $Z=-2.315$ ,  $p<.05$ ), from 22% to 26%. The difference between experimental and comparison groups at T2 continued to be significant ( $U=77.5$ ,  $Z=-3.254$ ,  $p<.001$ ). Examination of these data showed that one individual in the comparison group – a man aged 69 – had increased his score on the BDS by 46% of the maximum, far more than anyone else in either group. If this individual is removed the increase in BDS score for the comparison group is not significant ( $Z=-1.835$ , n.s.).

## **Discussion**

The data on active support and resident engagement in this study were collected by observers rating staff and resident behaviour during a visit to each home. Although inter-rater reliability was good, some caution should be exercised over the validity of these data because they were not collected independently. There is, therefore, the possibility that observers rated engagement as occurring more extensively when they rated more active support. In the absence of independent data (eg contemporaneous time-sample observation collected by others) it is not possible to rule this out. However, the data on adaptive behaviour was completed independently by residential care staff. Significantly higher scores were found in the experimental group at T2, which is consistent with the results of observation of support and engagement.

At the outset, the services in the experimental group were just beginning to implement active support. On average, staff support to residents was mainly rated as weak and inconsistent (eg “Activities not prepared (so clients kept waiting or have ‘false starts’) or clumsily presented (eg too tentative or too oppressive)”; “Occasional assistance from staff or assistance of only one level (eg instructions) provided”). Although they were beginning to influence the extent of engagement in meaningful activity by some service users, this was not sufficient to show on the measure used here. Residents were still spending almost all their time disengaged.

After three years, implementation of active support in the experimental group had increased substantially. On average, staff support was mainly rated as mixed

(eg “Some opportunities to involve clients (eg in simple parts of tasks) taken but many missed”; “Staff plan as they go, co-ordinating and liaising but not planning ahead. Clients are sometimes accidentally lost between staff, activities overlooked.”). This was reflected in a significant increase in engagement. Though still spending the majority of their time disengaged, residents were rated, on average, as participating in some activities. Coupled with this increase in engagement, residents had improved their skills by a small but significant amount.

The comparison group showed no significant change over time in active support, engagement or, with the one exception noted, in adaptive behaviour. Their staff were rated on the active support measure as providing, on average, mixed to weak performance.

These results are consistent with studies of the projects where active support methods were developed (Felce et al., 1986; Felce & Perry, 1995; Mansell, 1994, 1995) and with experimental studies of active support training (Jones et al., 1999). They add further evidence that people with intellectual disabilities can engage in meaningful activities at home and in the community to a significantly greater extent when staff adopt working methods designed to enable and facilitate this. They also support earlier findings (Mansell, McGill, & Emerson, 2001) that enabling people with intellectual disabilities to engage in meaningful activities is associated with increased independence.

The data also point to one of the difficulties of improving the quality of residential care for people with intellectual disabilities. The organisation which provided these services set out its intention of adopting active support in 1996 (Tindall, 1999). By 2000, services in the experimental group in this study have made substantial progress with implementation but the comparison group have hardly changed at all. This is despite considerable energy expended by the organisation in promoting the adoption of active support methods (special training, inclusion in existing training for managers, a steering group, a special senior appointment to coordinate implementation).

Several possible explanations for lack of change may be relevant. At T2, residents in the comparison group in this study showed more evidence of social impairment than those in the experimental group. It may be that in this or other ways not studied at T1 the comparison group presented greater challenges to staff implementing active support. Secondly, implementation may have been incomplete, focusing on record keeping and reporting rather than actual changes in observable performance. There is some evidence that the on-the-job coaching or ‘practice leadership’ required of first-line managers in improving staff support to residents is harder for them to implement than other aspects of change (Jones et al., 2001).

Third, in so far as homes in the comparison group may have started to implement active support there may have been a failure of maintenance, as has been found elsewhere (Mansell et al., 1994; McGill & Mansell, 1995; Orłowska & Mansell, 1996). Factors implicated in the difficulty of introducing and

sustaining active support methods include: conflict between staff values and the working methods required (McGill & Mansell, 1995); the difficulty of working intensively with residents and the belief that other work is more valued (Mansell & Elliott, 2001); and beliefs that senior managers and commissioners of services only pay lip-service to the goal of improving resident quality of life (Mansell, 1996). In this case the charity undertook the data collection in 2000 partly to inform its implementation strategy. As well as providing training in active support it is changing its corporate objectives to more strongly identify implementation as a goal and it will reflect this in monitoring and reward systems.

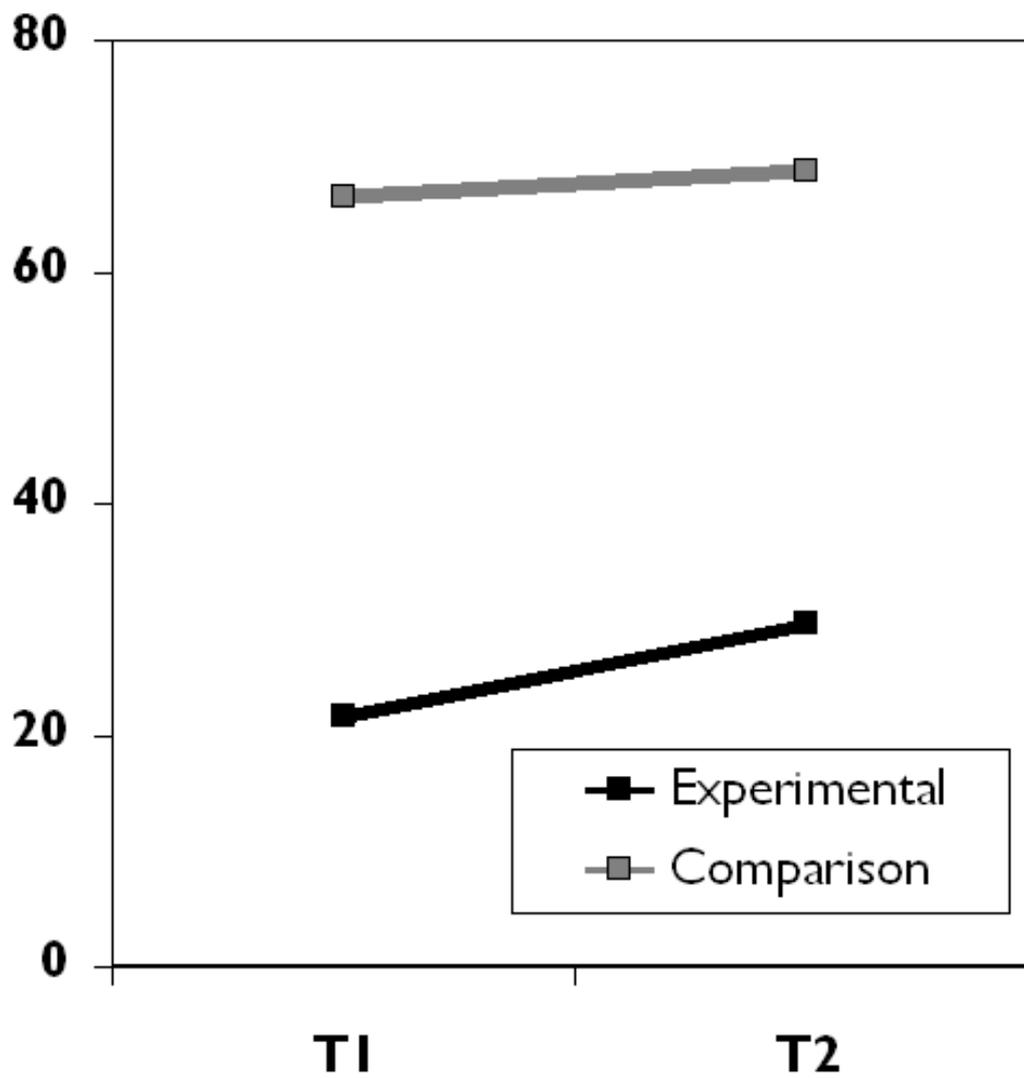
Table 1 Characteristics of participants and their homes

Descriptor	Experimental (n=23)	Comparison (n=26)
Age (Mean and range) <sup>1</sup>	39 (32-47)	39(20-69)
Gender (Percent male)	63%	42%
Ethnicity (Percent white)	96%	100%
BDS Adaptive Behavior <sup>2</sup>	28 (8-61)	38 (9-69)
BDS Maladaptive Behavior <sup>3</sup>	43 (23-55)	47 (36-56)
No of staff in house <sup>4</sup>	9 (6-12)	8 (5-12)
No of residents in house <sup>5</sup>	6 (4-7)	5 (3-10)

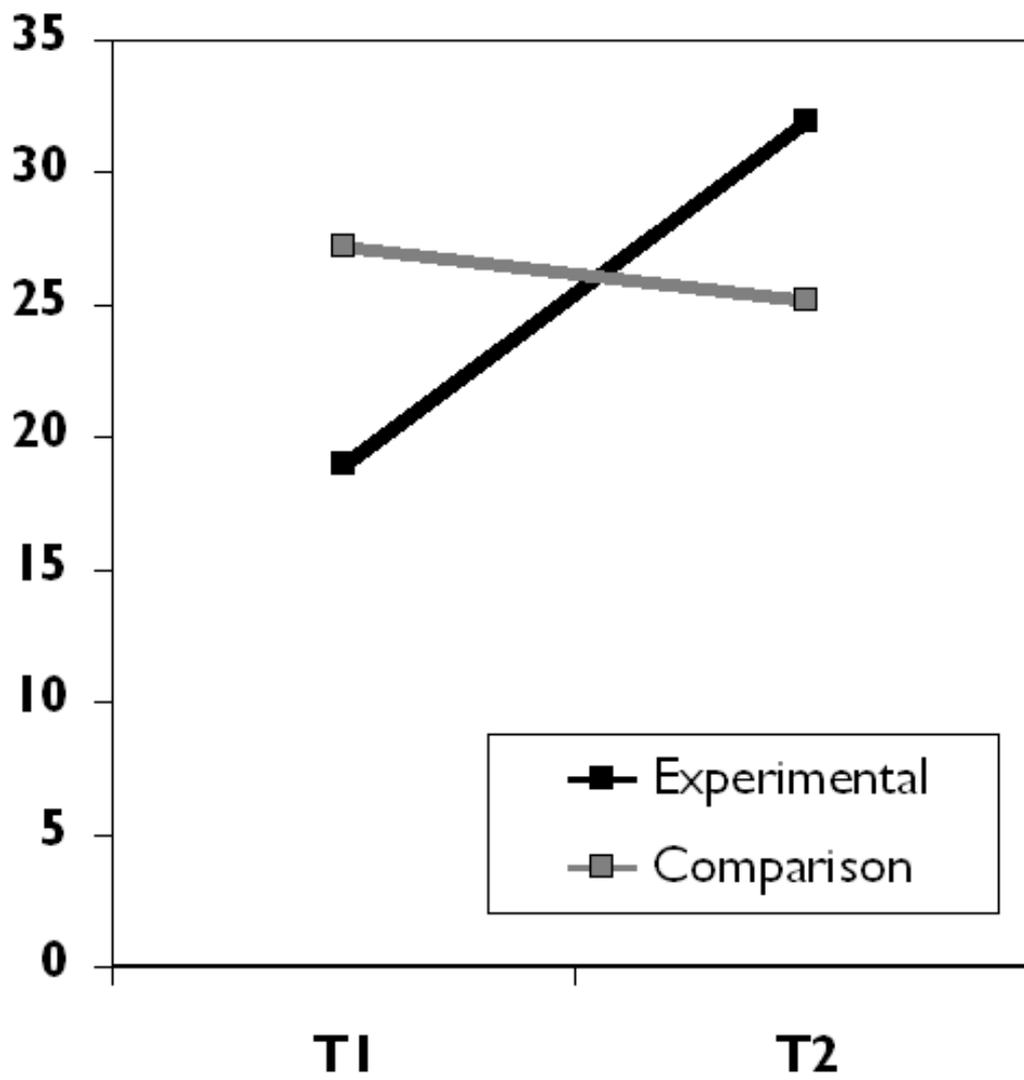
Notes:

- 1 t=0.130, df=47, n.s.
- 2 U=232, Z=-1.343, n.s.
- 3 U=197, Z=-1.665, n.s.
- 4 t=-1.56, df=47, n.s.
- 5 t=-1.137, df=47, n.s.

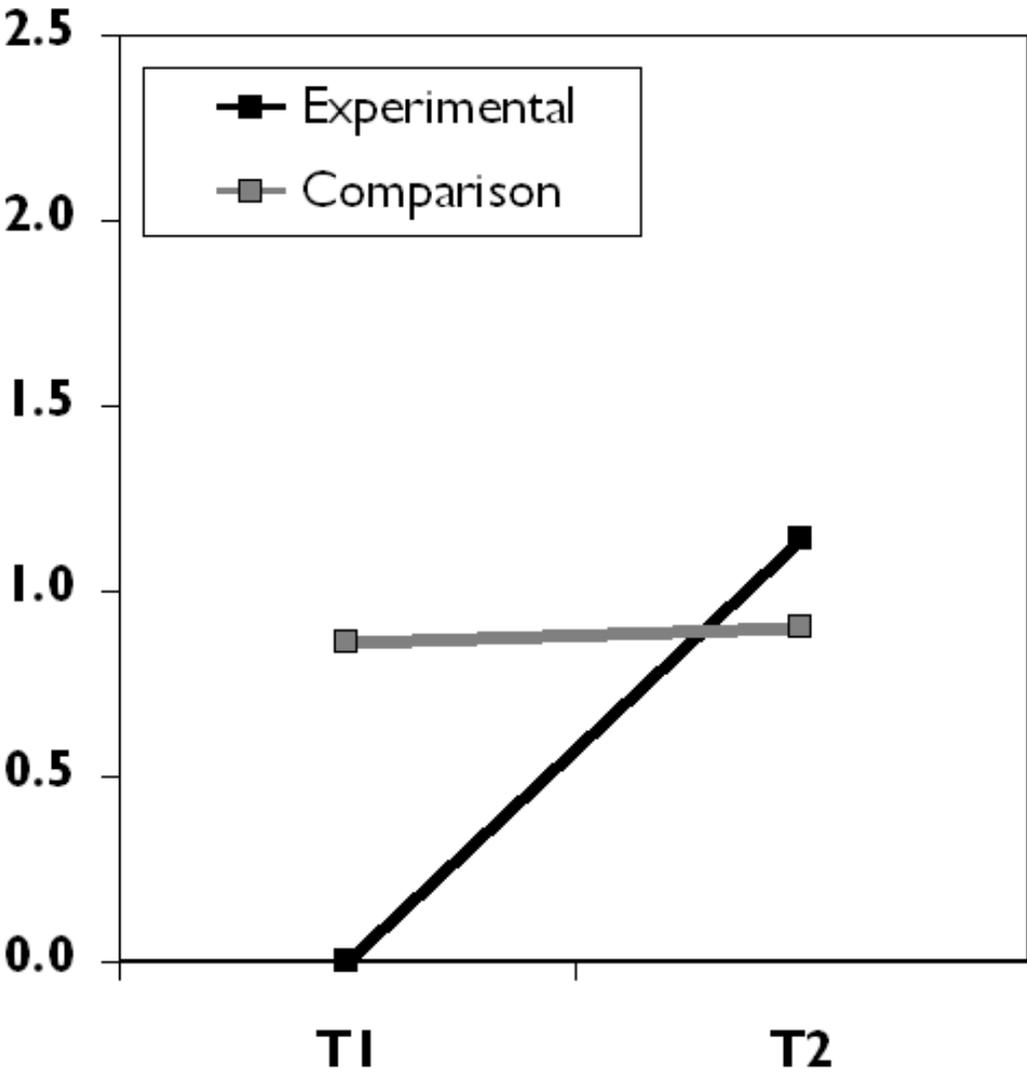
**Figure 1: Mean BDS at T1 and T2**



**Figure 2: Mean ASM at T1 and T2**



**Figure 3: Mean Engagement at T1 and T2**



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