JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/j.1365-2788.2009.01177.x

VOLUME 53 PART 8 pp 695–703 AUGUST 2009

Significant improvement in sleep in people with intellectual disabilities living in residential settings by non-pharmaceutical interventions

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Abstract

Background Although about 15 to 50 percent of people with intellectual disabilities (ID) living in residential settings suffer from sleep problems, scant attention is paid to these problems. Most available studies focus on pharmaceutical solutions. In this study we focus on improving sleep in people with intellectual disabilities living in residential settings by non-pharmaceutical interventions.
Method The design is a multiple case study using actigraphy. Following a baseline measurement of people with ID, we recommended an intervention such as bedtime scheduling. This was followed by an effect measurement.
Results Sleep efficiency, sleep latency and rising latency improved significantly. The time spent in bed also decreased significantly and the hours of sleep while in bed increased significantly.
Conclusion For people with ID, sleep can be improved by non-pharmaceutical interventions. A multidisciplinary approach is helpful in selecting an adequate intervention.

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Keywords actigraphy, intellectual disabilities, interventions, non-pharmaceutical, sleep problems

Introduction

Sleep problems are common among people with intellectual disabilities (ID). Studies using questionnaires and interviews have shown that about 15% to 50% of adults with ID and 58% to 80% of children with ID suffer from sleep problems (Barlett *et al.* 1985; Espie & Tweedie 1991; Brylewski & Wiggs 1998; Richdale *et al.* 2000). Sleep greatly affects the way we function in general, and good sleep positively influences the functioning of the immune system. To date hardly any research has been carried out into sleep problems in people with ID living in residential settings. Piazza *et al.* (1996) studied 51 children and adults with ID by means of time sampling. They found a higher sleep latency and a higher sleep fragmentation. People with ID *and* a severe behavioural disorder had the fewest hours of sleep per night. In a group of 293 people with ID, Lindblom *et al.* (2001) found a sleep efficiency index (calculated as the total sleep time in bed divided by the total time spent in bed) of 74%. A study by Espie *et al.* (1998) showed that, on average, people with a severe or profound ID would spend 42% of a 24-h period lying in bed. In

comparison with an age-related peer control group from the general population, the time spent in bed was significantly longer (10.40 h as opposed to 9.20 h). Electroencephalogram measurements and sleep diaries showed that this group of people with severe or profound ID had an average sleep efficiency of 82.8%. Didden *et al.* (2007) carried out research using actigraphy in a small group of people with ID. Similarly to Lindblom *et al.* (2001)they found a low sleep efficiency index (63%). Sleep latency in this study ranged from 19 min to 5 h 10 min.

Several studies clearly indicate that people with ID in residential facilities spend an enormous amount of time in bed. The results vary from 10 h 40 min (Espie *et al.* 1998) to 13 h (Didden *et al.* 2007). Espie *et al.* (1998) offered the following three possible explanations: the need for more hours of sleep in people with ID, the perceptions of the direct support staff (direct support professional, DSP) regarding this need and the circumstances of the care situation. Didden *et al.* (2007) found that the large amount of time these people spend in bed is more because of the way that routines are organised within residential settings than anything else.

A number of studies clearly show that care professionals assess their clients' sleep/wake cycles themselves, which might sometimes be incorrect (Mudford *et al.* 1997; Espie *et al.* 1998). Lack of understanding often causes them to mistake passivity and silent wakefulness for sleep (Mudford *et al.* 1997). Moreover, care professionals are often not aware of the effect that sleep problems have on the daily functioning of people with ID (Brylewski & Wiggs 1998). DSP have a tendency to overrate the sleep quality of people with ID (Espie *et al.* 1998). Moreover, in many residential settings clients are woken up during the night, sometimes as often as five times, so that incontinence care routines can be carried out (Carr & Neumann 1999). Studies on the impact of this practice in elderly care show that in 42% of the instances where clients were awake for 4 min or longer, noise, light and incontinence care events were the cause. Clients were woken up in 76% of the incontinence care routines (Cruise *et al.* 1998).

Relatively little intervention research into solving sleep problems has been carried out to date. Medication, in particular benzodiazepines, is sometimes administered for a long period of time (Kripke 2000). Melatonin is also administered (Braam *et al.* 2008; Dodd *et al.* 2008). Little information is available on research into behavioural interventions, with behavioural intervention research usually being confined to case studies (Curfs *et al.* 1999; Didden *et al.* 1999). In this study the research question is: can we improve sleep in people with ID living in residential settings using non-pharmaceutical interventions?

Method

Participants

Two large-scale residential organisations housing a total of 1700 clients in several small-scale facilities (from six up to 10 residents per unit) in the north of the Netherlands were asked to participate in the study. These organisations have a policy that night is a time for sleeping, meaning that incontinence care is only provided to those clients who are awake. Clients suffering from pressure ulcers are attended to irrespective of whether they are awake or not.

Both residential organisations had a multidisciplinary team (MDT) to deal with sleep problems. These teams comprised a physician, a psychologist, a health scientist and the night-duty head. If a DSP suspected a client of suffering from sleep problems, they reported this to the team by filling in the following forms:

- A registration form stating why they thought that the relevant client suffered from sleep problems;
- A sleep hygiene checklist, describing the client's sleep hygiene, for example, whether the client had his or her own bedroom and consumed drinks containing caffeine before going to bed;
- A survey of activities of the relevant client specifying both the type and number of activities carried out during the day;
- A sleep diary containing information such as bedtimes and whether the client was permitted to nap during the day; and
- A personal support plan describing the client, his or her additional disabilities, locomotor disabilities and the level of disability.

Over a 36-month period, 48 clients with suspected sleep problems were recommended by a

DSP for participation. Sleep problems were suspected on the basis of the number and duration of naps during the day, periods of wake during the night or problems with falling asleep. Prior to the inclusion in the study, baseline measurements were used to assess whether the clients had sufficient arm movement for valid Actiwatch measurements to be taken. Insufficient arm movement was an exclusion criterion, as was the use of sleep medication. Seven participants failed to meet the criterion of sufficient arm movement. None of the participants used sleep medication. Of the remaining 41 participants, 26 were male and 15 female. Their average age was 36.95 years (SD 17.38), and their level of intellectual functioning ranged from moderate to profound. Along with gender, age, level of ID and co-morbidity, the level of locomotor disability is presented in Table 1. Moderate locomotor disability means that the participant can walk or move with the help of a rollator or can move themselves in a wheelchair. Participants with a severe locomotor disability cannot move independently.

Instruments and procedure

For both the baseline measurement and the effect measurement we looked at sleep efficiency (total sleep time/time in bed multiplied by 100), sleep latency (the time it takes to fall asleep), the number of hours spent in bed and the number of hours slept. Sleep was measured by using the Actiwatch (type: activity) manufactured by Cambridge Neurotechnology Ltd. Actigraphy is an objective and relatively non-invasive method of measuring rest–activity patterns based on body movement. The associated software (Actiwatch Activity & Sleep Analysis version 5.32) estimates the sleep period. The Actiwatch is a small, lightweight device that is worn on the wrist like a wristwatch (Carvalho-Bos *et al.* 2007) and, in comparison with polysomnography, it is a valid instrument. While actigraphy has been found to have a tendency to overestimate total sleep time (Kushida *et al.* 2001; Wang *et al.* 2008), a comparison of sleep/wake scoring showed similar and fair agreement between polysomnography and actigraphy (Wang *et al.* 2008). In the present study, the epoch length was 0.5 min, and the Actiwatch was worn 24 h a day for 21 days. Instruction on the use and purpose of the Actiwatch was given before each period of measurement. The Actiwatches had an event marker button that was pressed at bedtime and upon rising. The health scientist subsequently calculated the measurement results and drew up a preliminary report based on those results. The relevant MDT then discussed the advice. Once consensus was reached, the team submitted the report to the psychologist or physician who requested the report and was responsible for implementing it. In most cases the report was also discussed with the client's DSP. The psychologist or physician who requested the report then reported back to the MDT after the recommendations had been followed. On average, the institutions followed the recommendations within 22.5 weeks (SD 9.3), after which a second measurement took place. The second measurement also had a duration of 24 h a day for 21 days. After this period there was a control measurement (T1) with the same Actiwatch.

Results

The results of the T0 measurement (first measurement, after intake) show that, on average, the participants spent 11 h 19 min lying in bed and that during that time they slept for an average of 8 h and 3 min (see Table 2). The average sleep efficiency was 71.8% (SD 14.75), and the average sleep latency 50 min (SD 44). The individual needs of each participant were then assessed with a view to improving their sleep efficiency and sleep latency. This was done during MDT meetings on the basis of recommendations made by the coordinator of the research group working within the MDTs of both participating institutions. The intake data, such as the personal report and the sleep diary, were compared with the results of the actigraphs and, if necessary, the recommendations made by the coordinator were amended during the meetings. Even though intervention was determined individually for each participant, there were similarities in the interventions offered. Five types of interventions can be distinguished: (1) sleep scheduling, which means that bedtimes correspond better to the participant's calendar age; (2) change in daily routine, meaning that activities were undertaken at a more suitable time; (3) activity during the day, meaning

Table 1 Characteristics of the participants

Participant	Gender	Age (years)	Level of intellectual disability	Level of locomotor disability	Co-morbidity	Number of weeks between T0 and T1	Type of Intervention
1	Male	44	Profound	Severe	Epilepsy	42	Other
2	Male	49	Severe	None	Visual impairment	21	Activity during the day
3	Male	57	Profound	Moderate	Epilepsy	26	Different daily routine
4	Male	16	Severe	None	Epilepsy	20	Sleep scheduling
5	Male	12	Moderate	None	ADHD	16	Sleep scheduling
6	Female	34	Moderate	None	Autistic spectrum disorder(ASD)	49	Other
7	Male	38	Severe	None	ASD	19	Sleep scheduling
8	Male	21	Severe	Severe	None	9	Sleep scheduling
9	Male	16	Moderate	None	ASD	40	Sleep scheduling
10	Male	14	Moderate	None	ASD	37	Sleep scheduling and activity during the day
11	Female	50	Severe	Moderate	None	21	Other
12	Male	28	Profound	Severe	Epilepsy & visual impairment	17	Activity during the day
13	Male	59	Profound	Moderate	Epilepsy	2	Activity during the day
14	Female	21	Severe	Moderate	Visual impairment	21	Sleep scheduling
15	Male	45	Severe	None	None	14	Sleep scheduling
16	Male	48	Severe	Moderate	None	27	Activity during the day
17	Female	66	Profound	Severe	None	17	Sleep scheduling and activity during the day
18	Male	22	Severe	Moderate	Epilepsy	30	Sleep scheduling and activity during the day
19	Male	26	Profound	Moderate	Epilepsy & ASD	22	Activity during the day
20	Female	10	Profound	Severe	Epilepsy	10	Sleep scheduling and activity during the day
21	Female	47	Profound	Moderate	Epilepsy	17	Sleep scheduling and activity during the day
22	Male	48	Profound	Severe	Epilepsy	33	Sleep scheduling
23	Male	52	Severe	None	Visual impairment	35	Sleep scheduling and activity during the day
24	Female	43	Profound	Severe	Epilepsy	25	Different daily routine
25	Male	42	Profound	Severe	Epilepsy	13	Sleep scheduling
26	Male	47	Profound	Moderate	None	22	Activity during the day
27	Male	25	Profound	Moderate	None	21	Activity during the day
28	Male	25	Profound	Severe	Epilepsy	21	Sleep scheduling
29	Female	64	Severe	Moderate	Visual impairment	25	Sleep scheduling and activity during the day
30	Male	58	Severe	Moderate	Alzheimer's disease	18	Sleep scheduling
31	Female	51	Severe	Moderate	None	21	Sleep scheduling
32	Female	37	Moderate	None	ASD	30	Sleep scheduling
33	Male	24	Severe	None	ASD	24	Activity during the day
34	Male	8	Profound	Moderate	none	13	Activity during the day
35	Female	21	Profound	Severe	Blind	21	Other
36	Female	14	Severe	Moderate	Visual impairment	17	Activity during the day
37	Female	56	Severe	Moderate	Visual impairment	31	Sleep scheduling and activity during the day
38	Male	31	Severe	None	ASD	12	Activity during the day
39	Female	63	Moderate	Moderate	None	21	Sleep scheduling
40	Female	63	Profound	None	ASD	23	Sleep scheduling
41	Male	19	Moderate	None	ASD	22	Sleep scheduling and activity during the day

Table 2 Sleep improvement results

Participant	Sleep efficiency index T0 (%)	Sleep efficiency index T1 (%)	Sleep latency T0 (min)	Sleep latency T1 (min)	Time in bed T0 (h : min)	Time in bed T1 (h : min)	Hours of sleep T0 (h : min)	Hours of sleep T1 (h : min)
1	30.10	42.79	152	60	12:22	12:35	3:27	5:24
2	53.30	74.69	129	16	13:26	11:23	7:04	8:29
3	67.52	81.23	46	21	10:49	10:53	7:17	8:51
4	77.16	74.15	36	34	10:37	11:51	8:14	8:47
5	74.26	82.61	25	16	11:43	10:46	8:45	8:53
6	83.08	86.36	38	23	11:26	11:11	9:30	9:38
7	71.31	80.25	39	18	10:52	9:33	7:46	7:44
8	68.90	73.01	19	5	10:41	10:27	7:20	7:35
9	79.26	73.01	63	18	10:26	10:28	8:16	8:56
10	79.28	84.27	16	12	11:05	10:17	8:45	8:37
11	78.48	80.88	53	40	9:02	9:46	7:06	7:52
12	80.88	73.25	18	21	10:39	10:33	8:36	7:43
13	83.88	90.15	26	4	10:56	10:14	9:10	9:13
14	84.63	89.75	22	12	12:01	10:59	10:09	9:50
15	85.27	82.27	16	22	11:22	11:08	9:41	9:07
16	49.93	69.46	57	33	11:39	11:15	5:48	7:45
17	88.13	91.66	13	6	13:08	11:53	10:32	10:54
18	90.09	91.24	12	8	12:15	11:26	11:00	10:25
19	85.54	84.47	9	13	10:46	11:09	9:12	10:00
20	77.53	72.83	31	25	12:24	11:27	9:36	8:21
21	76.17	84.81	60	46	10:12	10:54	7:47	8:42
22	33.91	34.31	75	34	12:05	10:45	4:12	4:07
23	79.99	93.67	31	2	12:37	12:11	10:05	11:25
24	48.95	69.51	183	101	11:07	10:46	5:30	7:33
25	60.72	69.81	144	48	12:40	10:15	7:43	7:07
26	76.41	76.52	7	16	10:52	10:31	8:17	8:02
27	74.52	88.43	23	22	10:20	9:59	7:42	8:49
28	81.11	86.58	32	21	12:43	11:52	10:19	10:15
29	87.44	88.31	5	6	11:49	10:46	10:23	9:32
30	58.97	78.64	95	22	10:52	8:13	5:34	6:38
31	76.06	81.89	18	11	12:00	10:30	9:03	8:30
32	77.78	83.95	18	10	10:02	9:10	7:52	7:41
33	64.21	75.05	69	35	10:03	9:50	6:27	7:24
34	69.85	73.56	36	91	12:12	11:58	8:34	8:47
35	62.54	69.09	49	32	10:47	10:11	6:44	7:00
36	79.31	97.94	95	5	10:34	10:47	8:41	10:33
37	40.99	64.27	97	34	11:41	11:08	4:47	7:09
38	81.94	87.88	17	7	10:13	9:18	8:21	8:09
39	61.31	75.40	112	40	10:51	8:49	6:37	6:37
40	87.68	74.20	12	14	11:29	11:32	10:03	8:34
41	77.83	75.53	53	35	11:12	10:02	8:42	7:34

an increase in the length of activities during the day, or more physical activities; (4) a combination of sleep scheduling and activities during the day; and (5) 'other' (see Table 1). Results for each participant are shown in Table 2.

In 15 cases, the sleep scheduling intervention resulted in bedtimes corresponding better to the participant's calendar age. In practice, this meant that most participants were taken to bed at a later time, but they had to be in bed before the start of

night duty, that is, before 10:15 PM. In two of the cases this was combined with a bedtime ritual. For instance, participant 5 was a 12-year-old boy who was admitted to a residential institution at the age of nine. He had a moderate ID and autistic spectrum disorder. On admission several agreements were made, which included the time that he was to go to bed. Subsequently, he was reported to have trouble falling asleep. During the first measurement, the boy was taken to bed at 7:45 PM, which was the agreed bedtime on admission. The intervention comprised making his bedtime 5 min later each day until it reached 8:45 PM. The reason for the step-by-step change of bedtime was his autism. Post-measurement showed that his sleep efficiency had increased from 74.2% to 82.6%, and his sleep onset latency had dropped from 25 to 16 min.

In two cases the daily routine was changed as it did not match the needs of the participants. An example is participant 3, a 57-year-old male with a profound ID who also suffered from epilepsy. He took unusually long naps in the afternoons, which was confirmed by the first Actiwatch measurement. Moreover, he appeared to be very lively and active in the evenings. He had to get up early so that he could be taken to the location where his daily activities took place. Around noon he would return to the institution, after which he usually fell asleep. He was frequently very active during the evenings, and it was assumed that his morning activities tired him out, causing inactivity and long naps in the afternoons. It was also difficult to wake him up in the mornings and, once awake, he seemed to find it difficult to get going. We recommended that he be offered activities at another time of the day. His daily activities were then shifted from the mornings to the afternoons, and he became the last person to be helped out of bed in the mornings. In the evenings he undertook other physical activities, such as walking and, finally, he was taken to bed later. We observed an increase in his sleep efficiency from 67.5% to 81.2% and a decrease in sleep onset latency from 46 to 21 min.

Ten participants were kept more active during the day, which resulted in a better night's sleep. For example, participant 36, a 14-year-old visually impaired girl with severe intellectual and moderate locomotor disabilities, had been extremely pampered during the day, had been allowed to take naps regularly and had few demands made of her. The first Actiwatch measurement showed a sleep efficiency of 79.3% and a sleep latency of 95 min. After discussions with the entire DSP team and her parents, it was decided to keep her as active as possible. Subsequently, the girl's sleep efficiency increased to 97.9%, and her sleep latency dropped to 5 min.

Sleep scheduling together with activities during the day were advised for nine participants, for example participant 37. She was a 56-year-old woman with severe ID. The results of the first Actiwatch measurement revealed that she spent a very long time bed (11 h and 41 min), her sleep efficiency was 40.99%, and her latency was 97 min. During the night she slept for only 4 h and 47 min. During the day she was very inactive. We recommended more suitable bedtimes in combination with more physical activity during the day. While her sleep efficiency increased to 64.27% and her latency decreased to 34 min, her time in bed improved very little (11 h and 8 min). However, as result of her more physical activities during the day she slept more hours (7 h and 9 min).

The intervention 'other' was offered in four cases. For example, participant 35 was a 21-year-old blind woman with profound intellectual and locomotor disabilities. Prior to intervention, she slept for much of the day and her sleep efficiency was 62.4% during the night. Furthermore, her average sleep latency was 49 min. The intake report showed that sensopathic activities were presented to her during the day, which included listening to music blended with the sounds of nature, for instance, wind in the trees and waterfalls. The intervention comprised leaving the music off during the day and turning it on when the client went to bed. Her sleep efficiency increased to 69%, while her sleep latency dropped to 32 min.

The results were analysed by using the paired samples *T*-test. Sleep efficiency increased in 33 of the 41 clients (80.5%), and sleep latency was reduced in 35 participants (85.3%). The whole group showed a significant improvement in their sleep efficiency (significance $\leq$0.000). The same applied to their sleep latency (significance $\leq$0.000) (see Table 3).

Most participants (80.5%) showed an increase in sleep efficiency and a decrease in sleep latency, but

Table 3 Average sleep improvement (standard deviation)

	T0	T1	Significance	*T*-values
Sleep efficiency index	71.8% (14.7)	78.5% (12)	<0.000	−5155
Sleep latency	50 min (43)	25 min (40)	<0.000	4439
Rising latency	15 min (18.9)	8 min (9.4)	0.009	2743
Time in bed	11:19 (0:56)	10:41 (0:55)	<0.000	4831
Hours of sleep	8:03 (1:46)	8:23 (1:26)	0.034	−2193

in eight cases the proposed interventions had no effect. In four of these eight cases (participants 9, 15, 40 and 41), it turned out that the proposed intervention had not been implemented. For the remaining four participants (participants 4, 12, 19 and 20), no demonstrable causes for the lack of effect could be established. Noteworthy however was the fact that all four suffered from epilepsy. In order to test whether epilepsy influences the effect of the intervention, a Wilcoxon signed-ranks test was performed. The group of participants with epilepsy ($n = 13$) was compared with the group of participants without epilepsy ($n = 28$). The results show that participants with epilepsy benefit less from the interventions than participants without epilepsy. Improvement in sleep latency was less significant (significance = 0.005); sleep efficiency was not significant (significance = 0.064). Improvement in hours in bed (significance = 0.184) and improvement in hours of sleep (significance = 0.422) were also not significant. We do not know whether these results were because of anticonvulsive medication or whether the epilepsy itself played a role.

Conclusion and discussion

This study shows that sleep problems can be alleviated by non-pharmaceutical interventions. In residential settings bedtimes are determined on the basis of staff work schedules rather than on the needs of the client. The primary focus in residential settings seems to be on daily functioning, whereas the connection between sleep and possible sleep problems is rarely made.

As do other studies (Espie *et al.* 1998; Didden *et al.* 2007), our study shows that people with ID in residential settings spend much time lying in bed. In this study we tried not only to make this clear to DSP, but also tried to do something about this. The results show that it is possible for clients to enjoy significantly better sleep as a result of improved sleep scheduling, a more suitable daily routine and/or increasing the number and extent of activities during the day.

After implementation of the interventions, participants still spent an average of 10 h 41 min lying in bed, and of this time an average of 2 h per night was spent lying awake. This means that the average sleep efficiency of 78.5% after the interventions is still low. Sleep efficiency percentages of between 85% and 88% are considered to indicate clinically significant sleep problems (Frankel *et al.* 1976; Coates *et al.* 1982). A number of intrinsic factors affect the quality of sleep. As demonstrated during this study, epilepsy is a significant obstacle. The literature shows that there are various factors that negatively influence sleep patterns, such as Alzheimer's disease (Reisberg & Gauthier 2008) and autism spectrum disorder (Schreck *et al.* 2004). The research literature also shows that visual disabilities have an unfavourable impact on sleep quality (Leger *et al.* 1999), but we have not been able to test this because of the limited number of participants with visual disabilities in this group.

Our research has various limitations. The selection of the participants was not carried out by the MDT. When sleep problems were suspected, participants were recommended to the MDT. The number of participants that were recommended by DSPs was limited, given the size of the population living in the facilities. Of a population of 1700, only 48 clients were recommended over a period of 36 months. None of these clients used sleep medication, but otherwise these participants were a very diverse group with respect to age, level of ID, level of motor ability and co-morbidity. Advice on the type and nature of the interventions was individually bound.

The Actiwatch has proved to be an extremely useful tool for conducting research into sleep problems in people with ID. However, it cannot be used on all clients. For example, those who have insufficient arm movement cannot use it. Sleep problems suffered by this group can be detected by using video or a sleep diary.

While we based this study on the assumption that better sleep quality will improve clients' functioning during the day and that behavioural improvement will occur naturally once sleep quality has improved, this study only focused on improvements in sleep quality.

The improved sleep quality in many of the study participants may have something to do with the multidisciplinary approach. As a result, the choice of intervention for each individual participant was discussed at length, which meant that support staff were given well-balanced intervention advice. The cooperation of management was important in this study as it meant that interventions could be effectively put into practice. During our study we noticed that the improved sleep quality also generated enthusiasm among the direct support staff. They saw the tangible figures of improvement as a reward for the efforts they had made to implement the recommendations of the research group. Their awareness of the impact the environment has on sleep of clients living in a residential setting is, to us, the most important result of our study.

Many people with ID living in residential settings spend half their lives lying in bed. Their daytime functioning depends largely on the quality of their sleep. More consideration needs to be given to sleep and sleep problems in people with ID. This study clearly shows that a number of problems can be prevented if care for people with ID focuses on their needs rather than on efficiency, such as adherence to fixed bedtimes. People with ID need carers who can work until midnight, so that the right circumstances can be created to ensure more normal sleep/wake patterns. In daily care practice, the focus should not be only on the improvement of care during the day but also during the night. This study also shows that sleep improvement interventions in residential settings can easily be put into practice provided the staff are committed.

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Accepted 9 April 2009