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One and Two Year Outcomes for Adults with Learning Disabilities Discharged to the Community

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Background. Long-stay patients with learning disabilities (n=214) were assessed in hospital and 12 and 24 months after discharge in order to examine the effects of relocation.

Method. Each resident acted as his/her own control in a prospective repeated-measures design. Skills and behavioural problems were assessed by keyworkers. Self-perceived quality of life was obtained during interviews with researchers who also completed an environmental checklist of the residents' accommodation.

Results. There was little or no change in people's low pre-discharge skill levels. Certain aspects of problem behaviour improved after 12 months, although socially unacceptable behaviour increased slightly. People were less depressed ($P \leqslant 0.01$) 12 months after discharge (n=119) and were more satisfied ($P \leqslant 0.05$) with their new 'homes' (n=108). There were few changes in the pattern of activities or the social networks of people 12 months later. Little or no further change in outcomes was reported 24 months after discharge.

Conclusions. The implementation of the deinstitutionalisation policy in Northern Ireland has been limited by the predominance of residential and nursing homes and the lack of 'ordinary' accommodation. There is a need for purchasers and providers to give more attention to ways in which the principles of normalisation could be incorporated in the process of contracting and delivering services.

The Regional Strategy for Health and Social Wellbeing in Northern Ireland, 1997–2002 proposes that: "Each Board and Trust should develop a comprehensive range of supportive services to people with a learning disability and their carers; the aim being to reduce to zero by 2002 the number of long-stay patients in hospital" (DHSS (NI), 1995). The modest five-year target reduction (set by the DHSS (NI) in 1987) of 20% in the number of people in long-stay mental handicap (and psychiatric) hospitals had been achieved by 1992. However, little was known about the effects of relocation on those leaving hospital.

The study reported here was carried out as part of a larger evaluation of community care for those discharged from the three mental handicap hospitals and six psychiatric hospitals in Northern Ireland between 1987 and 1992 (Donnelly *et al*, 1994). A separate paper (Beecham *et al*, 1996) provides information on the cost-effectiveness of community care for people with learning disabilties. During this time, 497 people with learning disabilities left hospital. However, those who were discharged later in the period (i.e. in 1990–1992) provided the main focus for the analysis as they could be followed up and assessed both before and after leaving hospital.

Method

In total, 214 people with learning disabilities who had spent one year or more in hospital were discharged between April 1990 and June 1992. Almost-two-thirds of this group were discharged to private nursing homes. The remainder were relocated mainly to residential homes provided by the private (12%) or voluntary sectors (10%) and to statutory hostels/group homes (13%) (see Table 1). Only five people (2%) went to some form of independent living. By the time the 12 month follow-up assessment was due, 14 people (6%) had been re-admitted to hospital owing to behavioural problems such as 'aggressiveness' and 'antisocial conduct'. Four former patients (2%) died during the first year after discharge.

It was possible within the timescale of the study to follow up 127 people 24 months after discharge. Of these, 86% were still in the community, 9% had been re-admitted to hospital and a further four people (3%) had died. The study concentrated on people who were discharged and who continued to reside in the community. Unfortunately, only limited information was collected on people who were re-admitted to hospital or who died during the two-year follow-up period. However, there was no evidence to indicate that any former long-stay resident discharged in the two-year period had become homeless or been imprisoned nor was there any evidence of suicide, neglect or abuse.

Procedure

People were assessed before discharge, after 12 months and, for a reduced (and therefore less representative) sub-sample, 24 months after leaving hospital. The instruments have been used in other large-scale evaluations of community care (Knapp *et al*, 1992). Only residents capable of communicating with researchers participated in the assessments of self-perceived quality of life. The number of respondents also varied due to re-admissions and deaths.

*The Social Functioning Questionnaire (SFQ; Clifford, 1987*b*)*

Ability to perform basic activities of daily living was recorded by key staff. The SFQ assesses self-care, domestic, community, social, and responsibility skills. Each skill category comprises a number of items scored from 1 to 4; higher scores indicate better skill levels. Measures of overall skill levels and of ability in each of the five component areas were calculated using mean scores. Staff were also asked to provide their own global ratings of overall and component skills.

*The Problems Questionnaire (PQ; Clifford, 1987*a*)*

The PQ was used by key staff to provide an assessment of: dangerousness; psychological impairment; management problems; socially unacceptable behaviour; and problems relating to attitudes and relationships. Items on each dimension are rated on a scale of 0 (indicating no problems) to 5 (indicating very serious problems). Mean scores were computed for overall behaviour and for each of the five behavioural dimensions. Global ratings of each were also provided by key staff.

The Residents' Interview (RI; Knapp et al, *1992)*

The RI (which is confidential and entirely voluntary) was modelled on the Interview for Morale and Life Satisfaction. It includes three widely used instruments designed to assess morale and life satisfaction: (a) Respondents are asked to indicate their overall satisfaction with life by selecting one of seven simple line drawings depicting three happy faces, three sad faces and one face with a neutral expression. This scale was modelled on Cantril's Ladder (Cantril, 1965); (b) the Psychosocial Functioning Inventory (PFI; Feragne *et al*, 1983) comprises 17 questions recording the frequency (i.e. 'often', 'sometimes' or 'never'; scored from 0 to 2) with which a respondent has experienced a range of positive/negative emotions (e.g. loneliness, boredom, happiness) during the previous month. Potential scores range from 0 (low morale) to 34 (high morale); and (c) the Depression Inventory (DI; Snaith *et al*, 1971) records the extent to which an individual experiences any of 12 symptoms representative of depressive illness. Each is rated on a four-point scale from 0 to 3 (i.e. 'definitely',

Table 1
Destination on discharge and place of residence 12 months later

Community accommodation	Number discharged 1990–1992	Number still resident in the community 12 months after discharge	Number re-admitted and still in hospital 12 months after discharge	Number who died in first 12 months
Statutory				
Hostel/Group home	28	26	1	–
Residential accommodation	2	2	–	–
Private				
Residential accommodation	25	21	2	1
Nursing home	130	120	10	2
Voluntary				
Hostel/Group home	2	2	–	–
Residential accommodation	22	20	1	1
Independent living	5	5	–	–
Total	214	196	14	4

'sometimes' 'not much' and 'not at all' respectively) to provide an overall measure of depression.

The RI also contains a section, based on a questionnaire by Seltzer & Seltzer (1983), which assesses clients' satisfaction with their living circumstances. Respondents were asked to indicate whether they liked or disliked 14 different aspects of their place of residence (e.g. food). These individual responses were recoded as either positive (+1) or negative (−1) and summed to provide a mean 'satisfaction with home environment' score. Additional questions assess clients' preferences for alternative accommodation; their network of social contacts; and the way in which they spend their day.

The Environment Checklist (EC; Knapp et al, *1992)*

An assessment of the quality of the living environment was carried out based on researcher observation and discussion with residents. The 50-item checklist provides information on the physical and social aspects of settings. It also includes the Sheltered Care Environment Scale (Lehman, 1983) which provides further information on the nature of the regime in hospital and community settings. Each item is coded 1 for a desirable feature and 0 for an undesirable feature to give an overall score for each setting ranging from 0 to 36. Higher scores indicate more desirable environments.

Results

The Kolmogorov–Smirnov test for goodness of fit showed that, in most cases, the pre- and post-discharge scores were not normally distributed. Thus, unless otherwise stated, non-parametric tests were used to test for differences between the pre-discharge and 12 and 24 month scores.

Daily living skills and social functioning (SFQ)

A substantial proportion of those discharged had a 'major problem', both in hospital and 12 months later with at least some of the 51 items included in the SFQ. For example, at 12 months, more than half experienced major problems with cooking, using the telephone and using public offices. The greatest skills deficits both before and after discharge, as indicated by global ratings, were in the areas of domestic and community living skills. Analysis of the component skill measures using matched *t*-tests revealed little or no overall change in the generally low skill levels between the hospital and 12-month assessments ($P<0.10$) (see Table 2). Skills scores after 12 months did not differ by either age or gender, with the exception of social skills which were significantly higher for females (Mann–Whitney U-test, $P\leqslant 0.05$). Analysis of the 24 month data revealed a slight, but not statistically significant, improvement in overall skill levels ($P\leqslant 0.10$) and no changes on individual skill dimensions.

Behavioural problems (PQ)

More than two-thirds of those for whom data were available at 12 months did not have 50 of the 59 behavioural problems listed in the PQ. Behaviours which did present some difficulty included, for example, verbal abusiveness, poor concentration and attention-seeking behaviour. While the overall mean rating of problem behaviour showed no change between the hospital and 12-month assessments, the global rating provided by key workers showed a significant improvement (see Table 2). Examination of the composite scores on each dimension showed no change between hospital and the community except for a slight but non-significant decline in socially unacceptable behaviour ($P\leqslant 0.10$). However, the global ratings by staff of psychological problems showed a statistically significant improvement ($P\leqslant 0.01$) between the pre-discharge and 12-month follow-up assessments. The lack of change in the overall mean ratings of behaviour was sustained for those for whom data were available 24 months after discharge ($n=118$), although there was a significant deterioration in attitudes towards involvement in activities and relationships with other people ($P\leqslant 0.05$).

A particular source of concern was the finding in relation to dangerousness – defined in the PQ as a tendency to violence, self-harm, sexual assault, arson, suicidal preoccupations and threats of violence. Twenty per cent of the group were noted to have a problem with regard to dangerous behaviour at either the hospital or one year assessments. Furthermore, 25 people whose behaviour was not considered dangerous in hospital were rated as dangerous one year after discharge.

Morale and life satisfaction (RI)

There were no significant differences between the hospital and 12-month assessments on the 'scale of faces' or the PFI. However, scores on the DI indicated that people were generally less depressed after spending 12 months in the community (paired *t*-test, $P\leqslant 0.01$) (see Table 2). During the second year of community living, no further changes were recorded on any of the three instruments.

Table 2
Overall daily living skills, problem behaviours and morale/life satisfaction

Instrument	In hospital before discharge	After 12 months in community	Change between hospital and 12 months
Social Functioning Questionnaire:			
Overall measure of daily living skills			
Mean global score[1]	11.71	11.43	−0.25(NS)
Number of respondents	209	208	200
Problems Questionnaire:			
Overall problem behaviour			
Mean global score[1]	3.39	2.87	−0.502**
Number of respondents	211	209	205
'Faces'			
Mean score	4.33	4.56	+0.39(NS)
Number of respondents	99	115	84
Psychosocial Functioning Inventory			
Mean score	21.14	22.07	+0.79(NS)
Number of respondents	66	74	52
Depression Inventory			
Mean score	26.22	28.95	+2.21***
Number of respondents	65	75	53

1. Global ratings were based on a key worker's overall impression of their client.
***, $P \leqslant 0.01$; **, $P \leqslant 0.05$; NS, not significant.

Nature of hospital and community accommodation (EC)

Statistically significant differences between hospital and community settings were found on all environmental features included in the EC (McNemar test, $P \leqslant 0.01$). For example, almost all former patients (98%) were living in community settings located near 'ordinary housing', while 79% were living close to public amenities.

Comparisons of the social aspects of settings showed that community facilities were better than hospital wards on a wide range of characteristics (McNemar test, $P \leqslant 0.01$). However, there were some mixed findings in this respect. For example, 40% of people were living in settings where staff wore uniforms. Almost all settings had a separate staff room or office (although 74% of residents had access to these rooms). On the other hand, high proportions of residents called staff by their first names (83%) and were encouraged to join in activities (93%). Despite some variation, only 27% were reported to be living in settings where the 'general regime' was judged, overall, to be institutional in nature. However, in most settings, there appeared to be a general mix of institutional versus 'home' approaches to care. For example, although three-quarters or more bought their own clothes and over half could choose their bedtimes, only 2% were allowed to have their own front door key. Furthermore, only small proportions of people shopped for their own food (4%) or cooked their own meals (11%), although 75% had a choice of food at mealtimes.

The Sheltered Care Environment Scale (Lehman, 1983) also showed that, on average, community facilities provided significantly greater opportunities for client autonomy and client–staff interaction ($P \leqslant 0.01$). For example, two-thirds of residents in the community were learning to do more things on their own compared to only a fifth in hospital (see Table 3). Overall, the community accommodation was judged to have features which were generally indicative of a favourable regime, although only around 15% of residents set up and took charge of their own activities (see Table 3).

Clients' own views of their community accommodation (RI)

Clients were also asked for their own views about their current place of residence. The data, available for only about 40% of the entire sample, showed that people's views about their accommodation had improved since leaving hospital, although there were some deteriorations, most notably those related to neighbours, access to town and facilities and having enough money (see Table 4). The

Table 3
Selected items from the Sheltered Care Environment Scale (Lehman, 1983)

Environmental characteristic	Hospital (n=214) (%)	Community (n=190) (%)
Residents receive individual attention	19	88
Residents set up their own activities	15	15
Staff are strict about the rules	20	19
Furniture is comfortable	25	96
Staff spend a lot of time with residents	38	93
Residents can get along without doing much for themselves	58	60
Residents have privacy whenever they want	18	68
Plenty of social activities	31	87
New skills are taught	16	48
Residents just seem to be passing the time	78	34
Residents are learning to do more things on their own	20	66
Residents encouraged to make their own decisions	20	53
Residents have say in making the rules	5	25
Residents sometimes take charge of activities	19	12
Residents can change things if they really try	1	19
Colour and decor make this a warm and cheerful place	18	87
Mean score Sheltered Environment Scale (for all 36 items)	15.14	23.44

overall rating of satisfaction with living environment showed a statistically significant improvement at the 12 month follow-up ($P \leqslant 0.05$). However, 20% indicated no change between the hospital and 12-month community assessments while 27% were less satisfied with their accommodation. Given that 90% were living in highly staffed homes, it was impossible to tell whether or not alternative accommodation might have been rated more highly by respondents. Furthermore, it was difficult to conduct tests of difference between types of community accommodation. However, three-quarters of respondents indicated that they were happy to stay in their present community accommodation while the same proportion, when in hospital, expressed a preference to live elsewhere. Analysis of the 24 month data showed that people continued to express significantly higher levels of satisfaction with their environment in the community than when in hospital ($P \leqslant 0.01$).

Social network and daytime activities (RI)

Overall, social networks and activities were unaltered following relocation to the community. The majority of people reported that they did not have any friends outside their place of residence in either hospital (74%) or the community (86%). Approximately 40% had no friends inside their place of residence either before or one year after discharge. However, the majority of people were in contact with relatives, though there was considerable variation in the frequency of visits to and from relatives. The most common activity in hospital was 'workshop activity' or occupational therapy followed by attendance at clubs and shopping. The same three activities were also the most common in the community, though participation rates were slightly higher.

Table 4
Satisfaction with home environment

Feature of environment	Positive views (%)		Change since hospital (%)	
	In hospital	12 months	Improved	Deteriorated
Home/hostel/ward	82	95	15	6
Comfort	89	98	11	0
Bedroom	94	97	5	4
Enough space	94	99	2	1
Food	89	96	7	4
Surrounding area	87	86	8	11
Neighbours	69	66	16	27
Access to town	70	81	17	13
Rules of establishment	83	94	12	7
Enough money	64	73	19	15
Feelings about possessions	95	96	7	4
Enough possessions	94	92	3	7
People live with	88	97	12	4
Staff	94	97	5	3
Number of respondents	107	110	84	84

Table 5
Regression analyses of overall daily living skills and behavioural problems 12 months after discharge from hospital

Explanatory variable	Overall skills		Behavioural problems	
	B	P	B	P
Constant term	1.63	0.00	3.18	0.00
Overall skills	0.84	0.00	−0.06	0.05
Behavioural problems (pre-discharge)			0.19	0.03
No mobility problems	0.72	0.05		
Profoundly handicapped	−1.33	0.02		
Age-inappropriate possessions common (hospital environment)	0.70	0.02		
Structure and decor pleasant (community environment)			−0.44	0.03
Sample size	119		142	
R^2	0.78		0.09	
F-test	98.72	0.00	4.61	0.01

Explaining changes over time

Multiple regression analyses and analysis of variance were used to examine the relationship between (a) overall daily living skills and (b) behavioural problems 12 months after leaving hospital, and a range of potential explanatory factors including: socio-demographic features (e.g. age at admission to hospital, gender and length of stay); pre-discharge scores on the SFQ and PQ; environmental features of community accommodation; service use in the community; community costs; and type and sector of community accommodation. The measures of morale and life satisfaction were not included in the set of regression analyses because of the reduced number and potentially biased nature of the subsample of people who completed an RI. Component measures of daily living skills were also excluded from the regression analyses because the subscores did not approximate to a normal distribution.

Strong links were found between skills when assessed in hospital and a year after discharge. After all other variables were held constant, skills at 12 months were higher for people without mobility problems and lower for people with a 'profound mental handicap' (see Table 5). The analysis also suggested that settings which encouraged residents to set up their own activities ($P < 0.14$) and allowed residents to entertain their own guests ($P < 0.08$) tended to produce higher (albeit not statistically significant) level of skills.

Only 9% of the variation in PQ scores was explained. People with better skills in hospital had fewer behavioural problems in the community; and a more pleasant environment was associated with fewer behavioural problems (see Table 5). The relationship between skills and behaviour and the type and sector of accommodation was difficult to unravel because of the significantly skewed distribution toward highly staffed homes.

Discussion

The research context

Comparatively few studies provide comprehensive, prospective evaluations of quality of life and welfare, but available evidence indicates that relocation leads to improvements in functioning, most notably in overall skill levels (Felce *et al*, 1985; Eastwood & Fisher, 1988). However, Cambridge *et al* (1994) reported apparent, although not statistically significant, deteriorations four years after discharge in behaviours such as odd gestures/mannerisms and attention-seeking. The evidence from this study indicates that former long-stay patients experienced few major problems adapting to community living. However, they had a generally low level of ability to perform basic activities of daily living and tended to be discharged to highly supportive accommodation where their skill levels remained largely unchanged. Community care in Northern Ireland for former long-stay hospital residents usually means 24-hour highly staffed homes – mostly provided by the private sector – a proportion of which appear to differ little from hospital environments. Although community homes were less institutional in character than hospital environments, people's lifestyles were similar in both settings in terms of the pattern of social contacts and daytime activities. Integration into the wider community was far from being achieved. There is a need to develop a fuller range of community environments based on the principles of normalisation as well as encouraging current settings to implement approaches to care which further develop people's skills and autonomy. The predominance of highly staffed settings precluded any meaningful analyses of possible differences in outcome across a range of accommodation.

Despite a modest increase in socially unacceptable behaviour after 12 months, there was a significant improvement in overall behaviour. However, this overall improvement concealed the fact that 25 people whose behaviour had not been rated as dangerous in hospital were so rated at the 12-month follow-up assessment. This may have been due, in part, to the fact that some people were placed in accommodation which was not entirely appropriate to their needs. For example, the capacity to tolerate more challenging behaviours may be lower in more intimate community settings. However, it also suggests that dangerousness tends to fluctuate over time and, therefore, that certain "at-risk" individuals may need close monitoring in the community.

Skill levels and behavioural problems after 12 months in the community were directly linked to those exhibited in hospital; this is predictable from the chronicity of the problems experienced by the group. While the variables included in the analyses explained approximately 78% of variation in skills levels, only 9% of variation in problem behaviours was explained suggesting that other factors may be at play.

The people in this study were similar to those discharged in the English Care in the Community Demonstration Programme (Knapp *et al*, 1992) on which the current study was largely modelled. For example, most were aged over 40 and had a 'medium grade' mental handicap (or IQ score of 20–49). However, in the English study there was evidence of a deterioration in behaviour 12 months after discharge although clients made notable improvements in their skills. In addition, this was one of only four studies which assessed, and reported significant increases in, morale and life satisfaction (Emerson & Hatton, 1994). Importantly, the findings presented here are based on an evaluation of people who were receiving only routinely available forms of support and care as opposed to the special demonstration projects in the English study. This may explain, in part, the better outcomes reported by Knapp *et al* (1992) which may have been the result of deploying a larger volume of resources to meet client need. Furthermore, the group of people discharged during 1990–1992 appeared more able than the remainder of the long-stay hospital population suggesting that the more dependent people who leave hospital in the future may have very different outcomes to those reported here. For example, antisocial and dangerous behaviour appeared to be the major factors influencing hospital staff recommendations for continued hospital placement (Donnelly *et al*, 1994). These findings provide support for the need to determine whether community-based provision is feasible for all those with learning disabilities (e.g. Department of Health, 1993).

Normalisation

In order that relocation and, to some extent "normalisation" (Wolfensberger, 1972) is successful, it is important that people, at the very least, retain the skills they possessed when in hospital and then have opportunities to use them when they move to the community. Furthermore, any deterioration in problem behaviour may jeopardise a stable community placement (Emerson *et al*, 1987), particularly since the opportunity for, and social consequences of, certain aspects of behaviour (including dangerousness) may vary greatly between hospital and community settings (Emerson & Hatton, 1994). Kleinberg & Galligan (1983) noted that the move to community living alone was insufficient to generate an improvement in skills and that the quality rather than the location of support was an important issue. The multivariate analyses suggest tentatively that those care settings which actively encouraged people to do more for themselves were more likely to promote skills development. Conversely, placements which failed to encourage mature behaviour were more likely to reduce skill levels relative to hospital. Clearly the more domestic settings represented a closer approximation to "normal" living and were more likely, therefore, to promote improvements in skills.

Policy and practice implications

It is likely that the pattern of relocation from hospital to private sector accommodation was influenced by the, then, impending changes to the system of funding community care. However, Health and Social Services Boards in Northern Ireland received special "bridging" funds between 1987 and 1992 to facilitate the development of appropriate community provision in anticipation of hospital run-down. Information about how this money was spent is difficult to obtain.

Quality community care means offering people the opportunity to move as their needs and preferences change. Emerson & Hatton (1994) noted that while the majority of studies reported an increase in 'personal competence' associated with relocation to smaller community-based provision, a third found no significant differences in skill levels across all accommodation types. The evidence from the study reported here suggests that greater effort should be made to expand the currently limited range of mainly residential provision. In addition, current accommodation could be enhanced by providing care regimes which further facilitate the development of skills and autonomous behaviour. It is likely that staff – many of whom have worked continuously for many years in hospital – require further support and training in order to provide a community service based on the principles of normalisation. The findings also indicate an increased need for clinicians and other care staff to give greater consideration to ways in which people might enjoy more of the kind of opportunities which lead to personal development but which involve a degree of risk. Possible fluctuations in dimensions of behaviour such as dangerousness also suggest that a sub-group of former patients may require careful pre-discharge assessment and ongoing monitoring after leaving hospital. It is likely, therefore, that the process of implementing community care will place considerable and continuing demands on clinicians and other care staff for some time to come.

Conclusion

There are a number of factors which should be kept in mind when interpreting the findings presented here. Firstly, the study was not an evaluation with clearly defined experimental and control groups. Former patients acted as their own controls. Assessments were carried out when both hospital and community settings were 'in transition'. It was not possible, therefore, to determine whether similar client outcomes to those seen would have occurred had people remained in hospital. Secondly, owing to the skewed nature of the discharge process and the lack of scope, therefore, for sub-group analysis, the research could not take account of all the factors which may influence client outcome. Finally, some of the findings were biased in favour of people with better communication skills.

In sum, there were no dramatic changes in the level of functioning or quality of life. However, it was not to be expected that relocation alone would produce marked changes in skills, behaviour and quality of life. The findings, therefore, provide some support for Allen's (1989) conclusion that "simply relocating people with mental handicaps into community settings is unlikely to have any lasting positive effect on their quality of life". The only personal benefits of community care, at least after the critical first 12 to 24 months, were observed in the fact that people reported feeling less depressed and preferred their new homes in the community.

Clinical implications

- There is a need for all health and social services staff to encourage and facilitate the development of care regimes based on the principles of normalisation in current community settings as well as developing a range of 'ordinary housing'.
- The successful development of community care is influenced by staff attitudes as well as appropriate resources. There is a need for staff to give particular consideration to ways in which people might be given more opportunity for personal development, mindful that this may involve a degree of risk.
- Certain 'at risk' individuals may need closer monitoring in the community owing to the fluctuating nature of their potentially dangerous and challenging behaviours; and assessments of future cohorts of discharges should take account of those aspects of behaviour likely to jeopardise community placement.

Limitations

- The evaluation did not include clearly defined experimental and control groups – patients acted as their own controls.
- The skewed nature of the discharge process (toward highly staffed forms of accommodation) prevented the kind of sub-group analysis required to explore in a detailed manner the relative effectiveness of different forms of community care.
- Findings related to clients' own views and self-reported morale are biased in favour of those with better communication skills.

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