

15 YEARS' EXPERIENCE OF MENTALLY HANDICAPPED CHILDREN LIVING IN TWO DOMESTIC COMMUNITY SETTINGS

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INTRODUCTION

The concept of mentally handicapped people, especially children, living in a normal domestic type environment is now well accepted and numerous examples are recorded, e.g. Allen et al. 1983; Wolfarth P. 1982.

However, the idea is not new. Oliver (1973) described a project which commenced in 1969. One of the developments described in this paper (Ivy Lodge) is the same as that included in the above report.

At the time of the initial consideration of the project, the results of the Brooklands experiment showing the benefits of placing children from a mental handicap hospital in a more stimulating environment were well known (Tizard, 1964), and the studies of King and Raynes (1968) of the care of various types of residential unit were being published. The impact of published criticism of the quality of care in long stay hospitals was also being felt (Morris 1969).

In 1969 the then Coleshill Hall Hospital Management Committee agreed to the conversion of a staff home (Ivy Lodge) to house a number of mentally handicapped children who were at that time resident in the wards of Chelmsley Hospital near Birmingham, which was a hospital for the mentally handicapped.

IVY LODGE — DESIGN AND POLICY

The house was situated in the local village, Marston Green, about half a mile from the hospital. It was a large old house in a quarter of an acre of land, adjacent to normal housing, shops and bus routes close by.

The original plan was for it to house nine children but further thought led to the conclusion that six was a better number. The house was altered to allow three bedrooms on the first floor for the children and one for the residential staff. It was a policy decision for the bedrooms to be occupied by more than one child with shared cupboards and wardrobes. The kitchen and laundry area were enlarged and equipped with appropriate domestic type equipment, work surfaces and furnishings. The garden was equipped with "normal" play equipment. Trees, flower beds and fencing were left untouched. A suggestion to have a large fence to confine the children to the garden at the rear of the house was resisted as were a number of other safety measures (e.g. bars at upstairs windows). However, safety window catches were fitted and an external fire escape was erected.

The Houseparents

The background of the original houseparents (who were technically employed as nursing assistants) were from caring professions. The housefather was a qualified audiometrist and the housemother had been an unqualified matron in

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a boarding school. Neither had any special experience with mentally handicapped children. The marriage was childless.

They brought, therefore, a caring background unhindered by experience of traditional practise of caring for the mentally handicapped. They saw themselves as "uncle and aunt" rather than staff or mother and father. They were given as much autonomy as possible, had the unobtrusive backing and advice of a mental handicap nursing officer and an informal support group of a clinical psychologist, psychiatrist, paediatrician and social worker which advised on practices and monitored the progress of the children.

The houseparents were encouraged to do all that natural parents would do for their families in a normal home, including shopping, cleaning, gardening, simple household repairs etc. However, it soon became apparent that caring for six handicapped children was really too much, therefore, part-time domestic and gardening help was provided.

The Children

The children were selected from the wards on an empirical basis primarily based on an assessment of their potential ability to return home or to move on to another residential setting in the community. The children selected were already attending a hospital school and this component was continued, the children being escorted by the staff on foot or in a minibus in inclement weather.

Assessment

The physical and environmental management practises in existence in Ivy Lodge initially during the first eighteen months were assessed by Green (1971) and scored highly on Morris' (1969) indices of physical conditions and degree of comfort and homeliness and gave a score of zero in the Revised Child Management scale (King, Raynes, and Tizard 1971), indicating completely child orientated practices.

As well as being a provision of a real home in a family sized mixed sexed group of children, Ivy Lodge was also considered to have an on going training function geared towards maximising the children's social competence during their developmental period. In a parallel study Green (1976) examined the level of skill acquisitions on the Progress Assessment Chart (Gunzburg 1969) in a number of trainee units set up in hospitals, all but Ivy Lodge being in wards in mental handicap hospitals. Whilst improvements were recorded in most of the units, the changes in the children living in Ivy Lodge were most apparent.

In 1972 the original houseparents left to take up a post of greater responsibility elsewhere and were replaced initially on a temporary basis by two young state enrolled female nurses from the hospital.

Subjectively, the children did not appear to lose skills or deteriorate in any way so it became a policy decision for the two nurses to remain there. At the time the residential aspect of the care continued with "sleeping in" allowances for the staff concerned. The male influence within the home was maintained by regular input from the male friends of the home staff who were themselves members of the hospital professional staff.

The impact of the children's development of the change of staff from the house parents to qualified female nurses was in effect to produce no apparent change. The original monitoring group remained in existence and the accommodation was unchanged. Minor changes in the pattern did occur; for instance there was more help from the hospital department such as catering and supplies.

However, throughout this period the programme continued to be one aimed at providing as normal a life as possible. The main non-normal feature was the continued attendance of the children at the hospital school. Further detailed objective assessments were not repeated but routine multi-disciplinary reviews of progress were conducted six monthly and revealed continued progress in social and communication skills.

The programme and staffing continued basically unchanged from 1972 until 1975. There was only one change of client, one boy returning home to his family and another boy replacing him from the main hospital. However, in 1975 the children were transferred to a newly purchased and furnished house (Lyndon House) on the grounds that this property and potential programmes would be even more domestic and normalised with attendance at a community special school, and the home more physically separated from the hospital and less dependent on it for provision of services.

IVY LODGE (PHASE 2)

The advantage gained by the original residents led to the decision to continue Ivy Lodge with a new group of children from the Hospital. Therefore, the six children transferred were, as a group, more 'difficult' than the original group. (Three boys and three girls, age range seven to twelve years were chosen.) The selection again was based primarily on the assumption that the children developmentally most able to benefit should move. However, by the mid 1970's as with most hospitals, the population of resident children was declining and those remaining presented, in general, greater problems of management be they behavioural physical or medical. In any case, by this time as already indicated, the experience gained by staff with a nursing background over the previous few years also encouraged the belief that more difficult children could be successfully managed in a domestic environment.

There had also been the National Health Service reorganisation and the new District Management Team insisted that the unit should be staffed on a more traditional basis with charge nurse and separate night staff, on the grounds that the children now resident in the home presented more problems of management than could be safely coped with under the former rather unconventional staffing system. During the subsequent years, four of the children remained throughout.

OBSERVATIONS ON THE EXPERIENCE WITH IVY LODGE

PHASE I (1969-75)

The group of children in this phase all appeared to make progress in a wide range of skills. This was particularly evident in the early stages.

The change of staff from house parents with a non-nursing background to young women with mental handicap nurse training and experience appeared to make little or no difference to the progress of the children. The monitoring of the unit

by a multidisciplinary support group throughout probably assisted in keeping standards of care at the same level.

An unanticipated issue occurred as a result of the way the original group was selected. As already stated, they were chosen for their greater level of basic skills on the assumption that after further training discharge home or elsewhere might be possible. Inadequate attention was given to the social circumstances of their families and the way these might influence potential for discharge. For example, three of the most able children could in fact have been regarded as basically rejected by their families, two of which were in Social Class I. Interestingly, the only direct discharge home from this group occurred with a child whose family had many social and financial problems but who with practical help and long term support were willing and able to receive the child back home.

It must also be recalled that these children moved to Ivy Lodge in 1969. At that time there was not the present interest or experience of fostering mentally handicapped children. Nowadays, most would probably be considered as being suitable for a foster placement.

Finally, an unmeasurable but very definite feeling of greater confidence by the support team in the ability of the staff to manage in a wider variety of clinical circumstances occurred. A number of minor emotional problems in the children soon resolved after the qualified staff nurses took up post.

In retrospect, it seems that more emphasis on training for the original house-parents may have borne fruit and allowed an even more effective harnessing of their undoubted drive and talent in child care. This is an issue stressed by Allen (1983) and many others. Nevertheless, it cannot be denied that given the specific circumstances of the Ivy Lodge project, the trained nursing experience of the later staff brought a greater tolerance of abnormal behaviour; and an ability to work with and effectively use support services, whilst still encouraging the children's development. This observation strengthened the support teams case for developing the second project (Lyndon House) and continuing Ivy Lodge for a new and potentially more difficult group of children.

PHASE II — (1975-84)

The nine children who were resident for all or part of the period 1975 to 1984 were a much more mixed group both in ability and in the problems of management they presented.

Table A would suggest empirically that most had shown an improvement in social and in personal skills, and in behaviour. Of course, there is no way of proving that they would not have shown similar progress in other settings, even if they had remained in the hospital ward. However, evidence elsewhere would suggest that this was not merely due to chance or just normal maturation (Oswin 1978).

The nursing staff during this period, most of whom also had previous experience in traditional hospitals, were in no doubt that the domestic setting had aided them in achieving a more effective delivery of care and assisted the children in reaching higher standards of personal achievement and social awareness.

An anecdotal but independent and perceptive account of Ivy Lodge given by McCormack (1979) appears to indicate that the basic normalised style of care continued throughout Phase 2 although the extended time that McCormack spent with the children and staff also revealed inconsistency in management did occur, often due to such typical events as staff shortages, which might also have occurred in Phase 1 but were not picked up by the more "scientific approach" employed then. The report also highlighted the danger of professional isolation of qualified staff and the risk to career advancement. These factors will presumably become less relevant when care in small units and an effective professional support network becomes the norm rather than the exception.

It cannot be denied that there have been failures in that two children had to return to a hospital ward because of major behavioural problems. However it was also noted that for most of the period the project was essentially a medical and nursing one. The deeper involvement of other therapists in direct care for a longer period might have enabled more progress to be made.

The deliberate development of a support group from the outset was seen as a common sense measure at the time. The importance of support staff has subsequently been stressed by Firth (1983).

Finally, on the assumption that normalisation, small group living and personalised delivery of care are now considered as highly desirable and effective in raising the level of skills in mentally handicapped people and enhancing their quality of life, the existence of Ivy Lodge must be considered successful.

OBSERVATIONS ON LYNDON HOUSE

PHASE I (1975-82)

This property was opened in 1975. It was previously owned by the Police Authority and consisted of two 3 bedrooomed, two storey houses joined on the ground floor by a small office. It is situated in an ordinary street with similar quality detached and semi-detached houses with a block of shops a few doors away and a larger shopping centre about a mile away. There is a reasonably sized garden at the rear backing onto the playing fields of a comprehensive school. No major developments were made to the home apart from providing modern kitchen furniture and fittings in one kitchen and a washing machine and deep freezer in the other. Central heating was changed from electric storage heaters to gas fired after the home was in use.

The initial group of children consisted, as already indicated, of five children from Ivy Lodge. They transferred from the hospital school to the local community special school. Their names were put on local general practitioners' lists.

From the outset, on the insistence of the District Management Team, the staffing was of traditional hospital style with a charge nurse, staff nurse and assistant nurses, a night shift, and separate cook and domestic staff. Sometimes the charge nurse needed to 'sleep in' to cover staff shortages.

Nevertheless, the policy of providing a normal domestic style of care continued and was made easier by the size and location of the unit. A small scale public relations exercise involving the local Residents Association led to the acceptance and subsequently positive support of Lyndon House and its residents

by the local community. During the years that followed, the children lived an apparently relatively rich, contented life and most made progress.

McCormack (1979) also studied Lyndon House and her conclusions were essentially the same as those concerning Ivy Lodge. The main advantage of Lyndon House seemed to stem primarily from the situation being physically more clearly within the community; for example with involvement of neighbours and attendance at a local community school.

Only one child returned back to Ivy Lodge and the Hospital School and that was because his behaviour led to exclusion from the community school and it was not possible for transport to be provided to go daily to another community school.

During their stay all the children were reviewed on a multidisciplinary basis involving home staff, school teachers, medical, social work and therapeutic staff.

Intensive efforts were made to place the children in alternative community accommodation. This proved a generally successful venture with all but two eventually returning to their families or to other community settings. This led to the idea that the time was approaching when such a home could be tried for short term care or on an "on demand" basis by mentally handicapped children living with their families locally, basically on the lines subsequently proposed by the Development Team for the Mentally Handicapped for the so called Community Units (1982). Therefore as the children began to be found places elsewhere the numbers in residence dropped and the empty beds were used on a small scale for the short term care which became rather disturbing for the remaining long stay residents, especially when there were only two of these left. Finally, only one remained and no alternative place could be found so he was transferred back to Ivy Lodge where he made further progress in a less stressful environment. The main observation made therefore at this stage was that long term residents in a small cohesive unit can in fact be disturbed and even overwhelmed by short term admissions, and probably see the situation as their home being invaded.

PHASE II (Short Term Care) 1982-84

As indicated above, the onset of this phase was a gradual process as the long-term children were discharged. All the beds did not come fully into use for short-term care until 1981.

In order to fulfil its new function as a residential support service to families living locally, it was decided to restrict admission to children living in the Metropolitan Borough of Solihull, with a population of approximately 200,000. Although the local Social Services Department has unusually well developed residential provision for mentally handicapped adults and a community support team, there was no statutory residential provision specifically for children. From the outset it was anticipated that the home might therefore be expected to take children with a wider range of problems and abilities. Consequently, a close liaison between the staff of the home, and professionals from the Health Authority and the Social Services Department was established.

A surprising finding, however, has been that more relatively able children with multiple handicaps. A small ground floor extension at the rear of the building has therefore recently been built and other minor modifications made to allow for more appropriate accommodation for such children.

At the time of writing the children of 70 families make use of Lyndon House. A comprehensive review of this phase may be the subject of future research. The research of Oswin (1981) would suggest that even this very domestic kind of provision for children may not be the most effective way of providing short term family relief and indeed may have previously little suspected disadvantages.

SUMMARY OF MAIN OBSERVATIONS ON THE USE OF DOMESTIC ACCOMMODATION FOR MENTALLY HANDICAPPED

- (1) The children benefit socially, behaviourally and in the development of personal skills.
- (2) The staff appear to gain benefit from caring for children in such circumstances. A lower absentee and staff turnover rates seems to support this contention.
- (3) The professional background of the staff in nursing is not in itself a contra-indication for child centre care.
- (4) Most children with a wide range of disabilities seem to be able to cope within such an environment.
- (5) Adaptations to accommodation may need to be made, for example, to provide extra ground floor accommodation and some more non-domestic equipment may be required, such as semi-industrial washing machines. It seems unnecessary to push the concept of "normal" domestic environment so far, for instance, that a stair lift instead of extra ground floor accommodation should be provided in order that the "normal" house structure was maintained.
- (6) The combination of a larger number of short term places with a small number of long term places in a small sized unit does not provide a satisfactory mix, particularly for the long stay children. A slightly larger unit with provision for separation might alleviate this problem but this would be seen as moving away from the basic concept of normalisation.
- (7) The selection of children for such a unit requires a judgement of the possibilities of eventual alternative accommodation and then this is probably more important than the basic ability of the children if successful rehabilitation is to be achieved.
- (8) Inadequate attention has been given so far to the family support needs, especially relief care of mildly mentally handicapped children with the result that a new facility intended primarily for the more severely retarded, might be put under considerable pressure to accept substantial numbers of the more able, thereby reducing its availability to those for whom it was intended. It is likely that short term fostering or similar schemes would provide a better arrangement for many families.
- (9) Nothing has arisen from this study that would indicate that this type of accommodation or style of care could not provide a satisfactory lifelong home for most people with a mental handicap.
- (10) It is probably necessary for such small units to have an unobtrusive but clear staff support system.

SUMMARY

A review has been made of the use of two different community based domestic sized premises for the residential care of children with a mental handicap. There seemed to be clear benefits for the children as well as for the staff. Other observations based on the 15 years experience are made.

Table A

Clinical State and Progress of Children during stay in Ivy Lodge — Phase 2

<i>Ini- tials</i>	<i>Clinical Picture</i>	<i>Feeding</i>	<i>Toilet</i>	<i>Dressing</i>	<i>Communi- cation</i>	<i>Behav- iour</i>	<i>Other Comments</i>	<i>Present Abode</i>
R.A.	Severe M.R. Epilepsy Hyperactive	+	++	+	+	++	More outgoing, relating better to others	Ivy Lodge
M.J.	Severe M.R.	++	+	+	+	-	Lately more aggressive behaviour. Transferred to Lyndon House & the returned.	Ivy Lodge
B.M.	Severe M.R. Autistic Features Self Mutilating	++	++	++	+	+	Was very withdrawn. Now relating well to adults especially. Self mutilation infrequent.	Ivy Lodge
G.M.	Severe M.R.	+	0	0	0	+	In Ivy Lodge for only 2 years. A shy tense boy. Gives impression of considerable potential but made little progress.	Ivy Lodge
N.M.	Severe M.R. Autistic Features	+	++	+	+	-		Ivy Lodge
J.K.	Severe M.R. Autistic Features Self Mutilating	+	0	+	+	-	Increasing aggression towards other residents led to transfer back to hospital.	Hospital
S.A.	Severe M.R. Small Mal-absorp- tion Syndrome	+	++	+	+	+	Timid personality, gained confidence.	L.A. Hostel
K.W.	Profound M.R. Hyperactive. Autis- tic features. Pica	0	+	0	0	0	Persistent behaviour problem. Could not be managed in home.	Hospital Ward

<i>Ini- tials</i>	<i>Clinical Picture</i>	<i>Feeding</i>	<i>Toilet</i>	<i>Dressing</i>	<i>Communi- cation</i>	<i>Behav- iour</i>	<i>Other Comments</i>	<i>Present Abode</i>
J.W.	Moderate M.R. Visual Defect	+	+	+	+	0		Pre-discharge Ward in Hospital
P.E.	Severe M.R. Overactive Aggressive	+	+	+	0	0	In Ivy Lodge for only last one year.	Ivy Lodge
C.H.	Mild/Moderate M.R. Downs Syndrome	++	++	++	++	++	Became very lively, outgoing and mature.	L.A. Hostel via Lyndon House
C.R.		++	++	+	+	+	Friendly character, learned new skills after stubbornness.	L.A. Hostel into Lyndon House
S.D.	Moderate M.R. Mild Hemiplegia	+	++	+	+	-	Stayed less than one year.	With own family
P.R.	Moderate M.R. Aggressive Episodes	++	++	+	+	+	Had episodes of regression apparently when pressure put on him. Improved after staff changed.	L.A. Hostel via Lyndon House
J.B.	Moderate/Severe M.R./Downs Syndrome	++	++	0	+	++		L.A. Hostel via Lyndon House
D.J.	Moderate	+	++	+	+	+		Voluntary Home via Lyndon House

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