

LETTERS TO THE EDITOR

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December 20, 1996

Dear Sir,

Robin Jackson in his review of 'Home at Last' (January 1996) is fully entitled to express concerns about a variety of quality of life issues inherent in the independent living setting described. What is disturbing in the review is not that he may hold differing views from myself or John Smith (Letter BJDD July 1996) regarding the desirability of congregate or communal residential provision, but the questionable way in which he has used the book to suggest that it has implications for policy with respect to other models of residential provision. "What the book demonstrates is that there is a need for a continuum of residential provision for young people and adults with learning disabilities." (p. 76). The book in no way demonstrates this, and the manner in which Mr. Jackson sets about making this inference cannot be allowed to pass unchallenged. Some of the principal points made in the review will suffice:

- i) Great play is made with the extent to which the choice of the independent living model was that of the two young women, Kathy and Victoria, as the parents assert, or the parents themselves. Mr. Jackson's claim (based on "a feeling") that the arrangements made "... met more closely

parents' wishes than daughters' needs" (p.76), is totally gratuitous. There is no way that on the basis of the book it can be substantiated. However, from this assumption Mr. Jackson then uses the tactic employed throughout the review to suggest that congregate care "may" have been preferred by the two young women: "If they had been able to communicate their feelings and preferences, Kathy and Victoria might have welcomed living in such a (congregate) setting . . .", (p. 76). This is to assume that they had not expressed their feelings and preferences, and on this Mr. Jackson actually has no information, least of all that they may have preferred more communal provision. The commitment of the parents involved in the 'Home at Last' initiative to independent advocacy gives the lie to any suggestion that it is their own interests rather than those of their daughters that they have set out to satisfy. There is, of course, a very serious and difficult issue here that Mr. Jackson does not comment on. In making provision for people with profound intellectual disabilities, there are clearly going to be areas where choices are required which have to reflect judgments made by informed decision makers, choices that are deemed in the best interest of the future resident

of whatever type of provision is contemplated. The basis for such decisions should always be substantiated by reference to preferences, behaviours and dispositions in the person, an inherently difficult process whether being undertaken by parents or professionals. (It should be added that neither Robin Jackson nor I would be able to provide a foolproof strategy by which two people with such disabilities could communicate relative preferences between different residential options.)

ii) Fitton *et al.* present an extraordinarily honest picture of the failures and successes in this venture, as Robin Jackson acknowledges. That picture, I would suggest, is no less problematical than for the millions living in inner city areas in the UK in the late 20th century. Why should honestly expressed difficulties be seen as a launching pad to suggest that the young women would be better placed in a more communal setting (I will avoid the word 'congregate' for a moment, but no, pace Mr. Jackson's letter BJDD July 1996, of course when I use the term "congregate" I am *not* referring to "... a small group of people living together".)? Both the young women, their parents, and the professionals involved are living in the real world where uncertainty exists and where there is an 'if' and a 'perhaps' round every corner. Read impartially, and not as a base to exploit a commitment to a spectrum of models of residential provision, there is nothing in the authors' meticulously honest account to suggest that Kathy and Victoria *would* be better placed elsewhere.

iii) It is saddening to find that the reviewer even uses Kathy's tragic death to speculate on why a different form of provision "might" have been preferable: "It is possible that the trauma resulting from the sad and premature death of Kathy and the consequent process of bereavement might have been mitigated . . . within a less isolated and insulated living arrangement." (p.76). Again, a purely speculative inference is made to argue for an alternative type of provision. I wonder if the reviewer on reflection has any reservations about using a young person's death to bolster in a such a tenuous way his case?

iv) And yes, the cost is high, but, most importantly revenue has been found. Is the implication that we should start with low revenue figures and tailor what is on offer from the outset? And yes, staffing problems exists, and are at least in part soluble (as Mr. Jackson could establish for himself by contacting the third author). None of these honestly presented difficulties "demonstrate" anything about the desirability or otherwise of one type of provision against an alternative.

Your reviewer has used every facet of an honest and deeply moving account, from finance to bereavement, as a launching pad to urge his own views. He is fully entitled to hold those views and engage in debate with respect to them. It is a pity he has chosen to do so in this way.

Yours faithfully,

Prof. James Hogg
Director

Aberdeenshire Representation & Advocacy Service
72a High Street
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17th January 1997

Dear Sir,

Professor Hogg in his letter of the 20th December 1996 takes me to task for 'the questionable way' in which I have used my review of *Home at Last* to suggest that the book's contents have implications for policy with respect to other models of residential provision. Perhaps I can draw Hogg's attention to the final paragraph in the authors' introduction:

'With the changes in assessment and provision coming about as a result of the 1990 Community Care legislation, we would hope that young people like Kathy, Victoria and Lisa will have all possible options examined for a fulfilling lifestyle. We hope this book will influence that process.'

I strongly endorse the authors' view that 'all possible options' should be examined but if policy makers are persuaded that the kind of model described in *Home at Last* is an answer then there would not be resources left to look at other options. Therefore the content of this book has direct implications for the provision of other models of residential provision.

If *Home at Last* had simply been a narrative account of what happened in the process of establishing an independent living project, as I understand had been the original intention, then I would have had less cause for critical comment. However, the decision to change the focus

and purpose of the book so that it is presented as a practical guide for those considering setting up similar projects entitles a reviewer to question the practicality and desirability of what is being proposed.

Hogg then turns to my questioning the extent to which the two young women were actively involved in their choice of home. In my review I make the simple point that had Kathy and Victoria been able to choose, would they have chosen Kendal House. Unlike Hogg, I don't pretend to know the answer. Whilst Hogg argues that it is wrong to speculate, he makes it quite clear that he knows what their choice would have been!

If Kathy and Victoria had been able to make an informed choice, is it seriously suggested that they would have chosen to live in a house which, because of the local high crime rate, was virtually sealed off from the neighbourhood in which it was located, with the result that the residents lived in a state of physical, social and psychological isolation. Hogg's response is that this is the kind of situation facing 'millions living in inner city areas in the UK in the late 20th century', which is a wildly exaggerated assertion. And whatever happened to the notion of providing clients with a fulfilling lifestyle within a congenial setting?

As to the sensitive issues surrounding Kathy's death and its consequences upon Victoria, the authors themselves

acknowledged the possible effects of isolation. They noted that after Kathy's death: 'Victoria was often more distressed than usual, and it was difficult to know how much this was grief, and how much the increased isolation, changes in her support workers and indeed the results of her complex epilepsy'. The authors further commented that: 'there was no one else in the house to chat with, or ask for advice or help, or share a joke'. (p.64). I believe that a reviewer is perfectly entitled to speculate on what might have been the effect on Victoria had she been living in a less isolated and closed unit.

I find the tone and content of Hogg's letter worrying on a number of counts. Firstly, it betrays a lack of tolerance to any kind of criticism. Secondly, I would have expected a greater measure of academic detachment from Professor Hogg in the presentation of his points! Whilst it is certainly true that I have argued the case for 'sheltered village communities' in the past, I have not done so out of any ideological commitment to this form of provision but from a belief that as wide a range of residential options as possible should be made available to adults with learning disabilities. I have never pretended that sheltered village communities provide the answer. I am content to leave it to readers of *Home at Last* to judge whether the residence in which Kathy and Victoria lived merited the description of 'a dream home'.

Yours faithfully

Dr Robin Jackson
Advocacy Co-ordinator
Banchory Office