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Abstract

This paper looks at some of the problems people experience when they are living independently. The study showed that problems are often associated with the area being lived in rather than with receiving poor support. **Keyword:**
Accommodation

'The neighbours aren't nice with me'

Consumers' comments on independent living

Margaret Flynn found that consumers living independently often have problems associated with their area, rather than with receiving poor support.

“Everybody in the shops know me. Nobody doesn't know me . . . I have a fella coming sometimes. He comes round to see me. There's no harm in having a boyfriend is there? I visit different people. See I go out and enjoy meself while I can. Some people don't like living on their own do they? I like it because I'm out most of the time . . . they're all friendly round here so that's the way I like it. I social work them and they social work me . . . I've been in homes and that. Didn't like them so I got out and did (went into) service.”

These comments came from a woman in her sixties who lived for many years in a hospital for people with a mental handicap. She is one of 88 people I met in an investigation of the lives and circumstances of people with a mental handicap living in their own homes in North West England funded by the Economic and Social Research Council.

Residential facilities

All 88 people whose lives were the focus of this study were known to their local social services departments and had lived in their own homes for at least a year. Most had spent vast periods of their lives in specialist residential facilities. Almost consistently, they spoke of

“I've been in homes and that. Didn't like them, so I got out and did service.”

their dislike of hospitals and hostels and said that they preferred to live in their own homes.

The following are typical observations concerning first a hospital, then a hostel:

“Horrible, weren't it horrible? Used to make you work they did.”

“It was alright to rehabilitate you to get you into society but you felt like children again. It was sort of like school.”

I worked with social services departments and community mental handicap

teams in six areas gathering information from social workers and case records. I systematically recorded information concerning people's histories, skills, current living circumstances, the frequency and type of support they receive, and their financial circumstances.



Illustration from 'Consumers as Colleagues' published by MIND

I visited everybody in their own homes, asked how they were managing and sought their views about their homes and neighbourhoods, income, daily activities and contact with other people. I noted their appearance, or more specifically their conspicuousness, and the implications of this for their lives, and made notes of such features as age and type of housing, state of repair, proximity to local facilities and rateable value.

Middle-aged

The 50 men and 38 women I met were largely middle-aged with a concentration of people over the age of 50. Twenty-six lived alone, 37 lived with one other person and 25 lived with two or more than two others. Their living situations in the main reflected their own preferences

There was no formal structure to the daily lives of 44 of the people in the study because they were either unemployed or retired. A lot of these had withdrawn from adult training centres and were critical of them. Criticisms focused largely upon inadequate payment, and being treated inappropriately. As one man observed:

“I was working it out, I was going there every day and I was getting 40p a day . . . it was costing me more than that in food because I've got to pay for me own dinners . . . Most of the time you had work in, some of the time you

“I was getting 40p a day . . . it was costing me more than that in food because I've got to pay for me own dinners.”

didn't . . . sometimes you were just sat there . . . and when I was coming home I had to rush out and get me food in and then get back to do the cleaning . . . You were sat there many a time with nothing, just a piece of paper and pen or summat. I mean, I don't mind drawing and that, but I mean the way half of them up there treat you at the centre, they treat you like a little kid, still at school you know. I mean I'm quite capable of working, only for me epileptics . . .”

The remaining subjects did have some structure to their day — 17 at ATCs; 12 in open employment; six in colleges. It is clear that this group was very poorly represented in the workforce.

Appearance

Some people 'stood out' because they were overweight, because of the way they walked or because their clothing was poorly cared for. A number had medical conditions that are associated with age, such as poor vision and walking problems. In terms of abilities, most could dress appropriately, use public transport and maintain proper sleep habits. Help was generally needed, however, with managing money and handling medical problems. The average weekly income was £39.

“She (sister) likes going round the shops so we go a lot on Saturdays. We go to Manchester a lot and buy things we need from there.”

“We feel that we could do with a bit more money you know. Like £42 doesn't really go far these days. What we buy out of that is like food, which takes a large part of it like clothing . . . shopkeepers, they don't consider the people that are classed as unemployed.”

“It was a shock when I first went out to get the first meal and he came with me. I said, 'The price of food, we'll have to live on bread and butter.' He said 'No well live on thin air!'”

Social workers were important to the group. Most regarded the social worker as their friend. They were on first name terms with each other and their contact was informal. About half either saw or had telephone contact with their social workers at least once a week. Social workers' main tasks were money management and monitoring health and hygiene. In general, the help provided by social workers was sensitive and responsive and people received the help they needed.

"Fran's taking me cat to the vet's to be done. It has to be done for my benefit and the cat's. She's something to do with social services, I can't think what."

"Social worker sorts me money out. It's Susan."

"When a bill comes we give it to June. She puts bulbs in for us when they go off, bulbs for lights . . . Yes, I like June, I've made a friend of her."

"Frank is going to learn me how to use the washing machine when he's got time 'cos I don't know how to use it you see. He showed May and Irene but I wasn't here you see."

Depressed areas

Most people lived in council rented property, over half in flats in either two storey or multi-storey buildings. The homes of a small number were in a poor state of repair. A quarter of those I met lived in 'hard to let' tenancies in areas in which rateable values were depressed. It alarmed and saddened me that a significant number were victimised. The most prevalent form of victimisation was name calling:

"I'm what's called mentally handicapped, a bit slow. I have some prob-

"June puts bulbs in for us when they go off. . . . Yes I like June, I've made a friend of her."

lems with the local kids. They say 'Out of the way fatso'."

"I've closed the curtains a few times and they've smashed me windows in . . . I'm dreading every night . . . The police are here more times than they're not . . . why do kids do it to some people and not to others? They've never bothered with the girl over the road or any of the others, it's always us."

My study isolated those factors associated with people doing well and those with people having difficulties. There are three key issues that have important implications for people living independently. These concern victimisation, daily activities, and social skills.

Victimisation Associated with residence in poor environments of run down housing stock, victimisation is more likely to happen to people who look conspicuous or different and to

those who are young. Its influence is pervasive and consistently damaging. People who are victimised are dissatisfied with their homes and yet fearful of leaving them. There are negative consequences for their relationships with others and they are more likely to be in debt. One woman had experienced victimisation over a number of years in a series of different tenancies, always in 'hard to let' areas.

Violence

"I get belted up and all sorts. There are 15 schools round here. They want to belt you or break your jaw in 'cause they hate you . . . My fella, he goes out and does the shopping because I'm scared of the children . . . they skit at me, at me stomach and me legs . . . They pick on us 'cause we can't talk properly and we're mentally handicapped or disabled . . . that's why they pick on me."

The message is clear. Individual qualities other than appearance are irrelevant to people's experience of victimisation. Preparation for independent living should embrace those aspects of appearance that we have some control over — weight, choice of dress, posture and walking. The paramount issue, however, is the location of a flat or house. This study has shown that a quarter of the population are living in 'hard to let' tenancies. This is too many. People need decent housing.

Daily activities Those with some structure to their days fare better than those who are either unemployed or retired. People occupied during the day are unlikely to have debts and more likely to be satisfied with their relationships and leisure activities. Some have voted with their feet and left their ATCs. They want jobs and to be treated as adults. Services need to access comprehensive special employment services, as a disproportionate number of people with disabilities are unemployed. The creative use of leisure should be explored and participation in locally based activities encouraged.

Old people's home

"I used to work in an old people's home . . . Well they wanted me to work for £4 a week . . . She wanted me to work Christmas Eve and Christmas Day. I mean £4 a week is not much . . . I enjoyed working at the old people's

home. I enjoyed talking to the old people, we used to have a laugh and a cup of tea . . . but I got the sack so I've got no job at all now . . . I started at a night club as a waitress but it was too much. Had to deal with pounds and stuff . . . I just get fed up because I've got no job."

Social skills Those with good interpersonal skills get along better than those who have not. They are more likely to express satisfaction with re-

"I enjoyed working at the old people's home. We used to have a laugh and a cup of tea."

lationships and to have enjoyable relationships with others. Support personnel must be attuned to people's social as well as practical needs. We all need contact with others and yet for varied reasons, this was not routine for a small number of the people I met. Some social workers were working towards the ultimate withdrawal of support. Given the limited social contacts of many subjects and their reliance on social workers as friends, this would seem to be a mistake.

It's a shame

"I like living on me own. I like this flat but the trouble is the neighbours are not nice with me. They won't let me be friends, I mean that upsets me a bit . . . What I feel in the flat is that it's a shame when you can't get on with people and I don't really you know. I don't really know really why. I mean when you can't go and see anybody and nobody come and see me, well you know the days seem to go longer and the nights seem to go longer as well."

When asked to rate the success of their clients, social workers described almost three-quarters as 'successful'. We must not lose sight of this when addressing some of the challenges of living independently. It is a formidable achievement for adults with a mental handicap. They want to live in their own homes and do not have fond memories of hospitals and hostels. Services must be attuned to environmental and individual factors when the placement of an adult with a mental handicap is considered. If they do not deal with the pitfalls identified by this study, an intolerable burden will be placed on people with a mental handicap, their families and service providers.

● The book of this study, *A Place of Me Own*, will be published in 1988 by Cassell. A summary of the research findings are available from Margaret Flynn at the Hester Adrian Research Centre, University of Manchester.

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