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REVIEWING DISABLED PEOPLE IN RESIDENTIAL CARE - WHAT DO WE MEAN?

Report of two Workshops held at the

King's Fund Centre

March 23rd and May 25th, 1982.

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King's Fund Centre
126 Albert Street
LONDON NW1 7NF

REVIEWING DISABLED PEOPLE IN RESIDENTIAL CARE - WHAT DO WE MEAN?

Tuesday March 23rd, 1982.

Introduction

Thirty-eight people took part in the first of two multi-disciplinary workshops on this theme organised by the Centre's Long Term Care Team. The workshops were intended as a follow-up of issues identified by the Residential Care Group which met during the International Year of Disabled People. Participants included headsof homes, matrons, nursing officers, therapists, care staff, social workers, residents and management committee members.

Setting The Scene

Dr Wendy Greengross, a Trustee of the Cheshire Foundation, explained that the organisation's philosophy was to allow people to be in charge of their own lives as much as possible. They had produced Handbooks of Care setting out this approach. The main principles were that there should be opportunity for:-

The person to assess the home.
The staff to assess the resident.
The staff and the person to assess the home.

The whole approach was based upon using resident's skills. Dr Greengross said they had been concerned as to how did one make decisions that were best for that resident - how did one work it out. Some people settled into residential care really well and made use of all the resources. Others, somehow, never 'get it together'. Dr Greengross emphasised that depression was often an important factor that was not realised or taken into account. It was vital to look under this, to give help and to make sure that aid was appropriate to the individual.

People go into residential care, not as an end, but as a beginning. In some cases there were difficulties because, for example, parents had done too much for a child and created dependency. The new setting could, if handled intelligently, be a growth point. All depended on the attitudes and the milieu. Some arrivals, such as accident victims, needed to learn how to expand their coping abilities whilst others, people with multiple sclerosis, for example, needed to be taught how to cope with a diminishing world.

The handbooks used the words 'assessment' and 'review' and Dr Greengross felt these were both equally unsatisfactory. But they were meant to express the idea of a growing point in the personal development of physically handicapped people.

What was clear was that the individual resident must be at the centre. Not so clear was the time factor - should the review be done yearly, or every two years, for example? By whom should it be done? By someone on the spot? Or by a social worker, coming in with a fresh eye, from outside the residential setting? Or should it be done another way, by the resident keeping a diary? It was important not just to look at skills but to consider emotions, perceptions and an inner sense of well-being. These suggestions, at least, offered a starting point.

Video 'Home From Home'

Instead of settling down comfortably with their notepads at this point workshop participants were jolted by the immediacy of a candid video from the Bristol Arts Project.

Residents' views of what its like to live in a hospital unit were terse:

'This is meant to be our home, but its more like a hospital ward'.
'We are really part of a crowd. We have no real individuality whatsoever. We do everything by the clock'.

Poor communications and training cause bad morale:

'I think this place is the best of a bad job', said a resident who complained: 'We are always being told how grateful we should be because we don't have to pay rates and mortgages'.

A lack of staff education, with ensuing attitudes, causes much resentment:

'Sometimes they treat us like Zombies' one resident said.
A domestic said 'Why don't you come and mop the floor for me? - If only I could', fumed the resident.
'Doctors and nurses have a weekly discussion and all our files are brought in. But we never get told anything'.

Privacy is a sensitive issue:

'Privacy is non-existent, especially if you have to share a room'.
'Lots of visitors come round our unit. They come and look through our doors and gawp at us, they are never introduced to us'.
'It all adds up to a feeling of vulnerability - lack of privacy'.

Secluded locations make residents feel the home is isolated and cut-off from town or village:

'You can't even have that friendly feeling of calling in at the corner shop'.

Poor design adds to dependency: Residents felt there was need for more consultation even on the simple things. They complained of the struggle to open doors and windows. Heating could be too overpowering and they felt it would be sensible for all rooms to have the possibility of individual regulation. Awkward siting of wall plugs meant that you had to ask the nurses to plug-in the television set and you didn't like having to ask them all the time.

Were there any compensations?

'Being a member of a group', said one resident.
'Being with my husband now we've got a double-room', said another.
Others replied:
'Going home for the week-end'.
'Can't think of any'.
'Best of a bad job - at least better than a geriatric unit'.

Asked what they wanted most, residents replied: 'Respect' and 'Not to be herded together'.

The video caused a spirited discussion. A physically handicapped student commented that the anger in the video spotlighted the problems of individuality, privacy and identity which were still very much the same as they were at the beginning of the century. She felt that people setting up the care thought it had improved yet we were still finding the same problems.

Workshop Chairman, Malcolm Johnson, asked was this because expectations were higher. The student believed they probably were. But the core of the matter was passivity and being on the receiving end all the time.

Another disabled participant felt the problem was that the people in the film were being treated as 'cases' instead of just as people who were disabled.

Wendy Greengross commented that when patients were given more chance of self-determination it makes it much more difficult for staff to cope. She believed much of the problem was due to the medical model. A very important aspect of trying to change things was the question of constraints around the individual.

Another participant asked was the level of dis-satisfaction shown in the video atypical? Wendy Greengross replied that she thought we had a long way to go.

A member of a residential home management committee asked what residential participation was there at the unit on the video and what control did residents have over their own lives? Pauline Tilley-Moxon, research director of the Bristol Arts Project, answered that residents were allowed to go to weekly medical meetings but only by invitation. The consultant would listen, but he was not actually based in the home. The staff with maximum contact were the nurses who were in the usual hierarchical position.

Wendy Greengross said it was perhaps easier to express your frustrations and resentments in a residential setting, than to your relatives trying to cope at home. This was a raw area. It was very difficult for staff to hear peoples' pain being expressed. Staff did need great support.

The student participant believed one way of putting in input for change was to use normal, generic services as much as possible. It was a good way of getting people out and helping them to look outwards to the community by giving them choice of their own doctor and dentist - and the chance to change if they didn't like them.

Why Do We Need Reviews? Who Benefits?

How more self-determination and independence could be given to residents was outlined by Dick Bailey, superintendent of the London Borough of Islington hostel at King Henry's Walk. Here, seventeen physically handicapped people, some residents and others living in flats and bungalows on a nearby housing estate, use a collective approach of maximum flexibility and self-determination. Staff roles are more blurred than in many places with gardeners and van drivers, for example, also working as carers. The residents and staff, working together, have evolved a way of increasing levels of independence.

There is no formal, fixed review formula - but the work-style is such that there is a continuing awareness of goals and progress and the need for feedback. The King Henry's Walk team tries to maximise the potential of every resident by giving resources that concentrate on the individual's abilities in an environment that encourages them to take risks. Said Dick Bailey: 'We all live lives with an element of choice and unpredictability in them - and disabled people should be able to do so, too, if they wish'.

Cautioning workshop members to beware of the Shibboleth of the "smooth-running" institution, Dick Bailey felt there was a need to be constantly on the alert in long-stay care to make sure that a unit did not actually add to a person's disablement - far too many did.

He advocated a continuing appraisal, or review in the round, looking at the whole unit, its facilities, atmosphere and entire environment including linkages as well as the attitudes and assumptions of residents and staff. Funding, other resources and outside help for individual people was all part of that appraisal. One of the most important aspects was to establish needs by drawing upon communications from residents and staff. Suggesting at least six-monthly reviews, Dick Bailey argued that circumstances must be reviewed frequently enough so that needs at that particular time are known adequately, because expectations and ambitions can change, sometimes fairly quickly.

King Henry's Walk reviews involve the resident, staff or key worker who work directly with that person, a worker from the social services department and the superintendent. People from outside are also drawn in, for example, the GP, or therapist, or people from college or other place of regular contact, also relatives. Only people that the resident wishes to attend are present and, in some cases, the staff leave the resident to organise the review. A key worker has specific responsibility for recording what occurs, preferably in consultation with the resident.

The King Henry's Walk team finds the system valuable in many ways. It is helpful for other workers to be involved so that they see progress, as well as problems, and are not just invoked if a crisis crops up. It is useful for staff and volunteers to be able to assess their performance and their value to that particular resident. It is helpful for residents to explore ideas, to suggest resources they would like to see made available and to be able to express their fears and resentments.

Who Does Reviews and When Are They Done?

Hazel Canter, of the Department of Health and Social Security, gave a preview of a research project on long-stay care called This Is Their Home. She said a totality of views gathered from 10 residential homes showed that the answers to the title of her workshop talk were 'Nobody much and not very often'.

The researchers found that there wasn't a lot of specific help given on useful aids which would have helped individuals to achieve more independence. This was really the most neglected practical area of all. Much of the equipment e.g. hoists, were for staff to use on residents.

Medical/physical reviews were, on the whole, not too badly arranged. Psychosocial reviews seemed mainly to be left to the senior staff and so this was where the outcome/evaluation rested. The researchers found problems were at ground level where residents and staff, lower in the hierarchy, were not getting feedback, or training, to help them in their attitudes. Because cleaning is deemed merely a work centred task domestics have to get the work done and in one instance tied a towel through the wheels of a wheelchair to prevent a resident impeding the job.

Another aspect revealed by the research was the problems of people left in their emotional pain. This was because there was a great feeling among staff of 'don't make waves' otherwise you upset people and, therefore, upset the status quo and smooth running.

There were particular emotional problems for residents who had had a stroke, lost their homes, become disabled unexpectedly and there were even more difficulties for people whose marriage had broken up as a result. One resident welcomed the chance to confide in a researcher saying: 'It's the first time since I came in here that I have really had a chance to talk about my feelings'.

Hazel Canter believed that residents' aspirations were also not taken into account sufficiently. There was great need to explore these and to try to get appropriate action. The aspirations confided to the researchers were extremely varied. One man wanted to have the pleasure of going down the road with a lovely looking woman but he had never had the opportunity. A young woman yearned to set-up home with her boyfriend in a specially-adapted bungalow but she did not know what was happening because it was in the hands of the council. Another resident told the researchers that she would like to die.

The paradox for staff was that if they succeeded in their goals to make people more independent, than you had residents who had higher expectations and would certainly be critical. Some of the residents felt able to be very rude to the researchers about their home.

General Discussion

Opening the discussion a participant asked how did you help the inarticulate achieve self-determination, whilst another disabled participant pinpointed the problem of how residents could avoid becoming institutionalised. People are dictated to at school, then for the disabled, the whole process starts all over again when they go into residential care. He believed there was tremendous need for reviews to look at the goals of moving-on to different types of place to live. Aids were not a panacea. If you had to struggle for 1 hour to dress, this can be extremely draining of energy which you might want to reserve for something more important to you.

A social worker mentioned the problems of those physically handicapped residents who were now getting very, very elderly. Wendy Greengross believed the concept of 'a home for life' was tremendously important for people to feel secure.

Reports from the workshop groups revealed wide differences of opinion. People against reviews felt the 'goldfish bowl syndrome' was the main danger. Those for them felt reviews with the residents taking part in the discussion gave them the feeling that they had some control over their own lives.

One group decided that they should all now go back and think about the question of reviews, whereas, before, the subject had never even been an issue.

Conclusion

In a lucid summing-up Malcolm Johnson said there had been a lively and diverse discussion of issues requiring a thorough airing. There was agreement that reviews should focus on individuals. They should be a two-way process looking at residents and the service. If there was a mis-match and something was out of equilibrium then this could be due to two sides. Reviews would vary according to the types of individual and the kind of staff. They needed to be flexible and should set sensible goals. They could be useful only if there could be an outcome or consequences. There was disagreement about the regularity of reviews and probably this was best left to local circumstances and residents' needs. The same thing applied to the initiative for reviews. Much would depend upon who the residents were and who the staff were - it should not be assumed that the very articulate residents participating in the workshop were representative.

Malcolm said it was clear that formal reviews were not generally favoured and there were ambivalent attitudes towards risk-taking. However, people needed to be able to take responsibility for themselves, if not everything we do is a sham.

Passing-on Peter Townsend's view that 'one way of extending lives is by extending tolerance' Malcolm Johnson said the central theme for long-stay carers is finding ways of loosening dependency and making the lives of disabled people less disabling in the total sense.

He thanked participants for being open with their prejudices so that people could react against them.

REVIEWING DISABLED PEOPLE IN RESIDENTIAL CARE - WHAT DO WE MEAN?

Tuesday May 25th, 1982.

Introduction

This second workshop was notable for a more hard-edged approach than the first. The 42 people who took part started from the premise that residents could scarcely be expected to spend many years, or a lifetime, in long-stay care without some sort of review. So this second workshop was able to focus in more closely on the nitty gritty questions of how, when and who by?

As before, the participants were drawn from a wide cross-section of the disciplines. They included nurses, ward sisters and doctors from hospital young disabled units, care staff, residential home and day centre managers as well as social workers and administrators. There was one counsellor and six residents. They were fairly equally divided between the statutory and voluntary sectors.

Welcoming the participants, Graham Cannon, Director of The King's Fund Centre, explained that the workshops were meant to give people neutral ground on which to have a free-ranging discussion. It was clear that the first workshop had been a success simply because 'everyone left very edgy and a lot of things got stirred up'.

Workshop Chairman, Malcolm Johnson, senior fellow at the Policies Study Institute, agreed that it was much easier to say things to each other on neutral territory than in the residential setting.

Warning that people who run workshops were not there just to make people feel better, he said that the most purposeful ones were those that managed to create that feeling of a little prickle under the skin and the thought that some things might have been best left unsaid. In a nutshell, the aim of the day was to deal with ways that could be used to counter-attack our prejudices and make our work better.

Setting The Scene

Starting from the basis that neither assessment nor review were ideal portmanteau words, Dr Wendy Greengross, a Trustee of The Cheshire Homes, confessed her own leaning was towards review. With assessment there was a scaling problem 'Do you pass or fail?'. She felt that there was something perjorative about it. Review, she felt, was a better word.

She asked participants to agree as common ground that there was need for review because in residential care there were a large number of people who were living below their fullest capacity. There was desperate need for more work to be done in the sphere of personal growth and development. In her characteristically fair-minded way Dr Greengross did not forget the other side of the coin - of course, there are also many disabled people living in their own homes who also live below their capacity. We must not fall into the fantasy that everything in peoples' own homes was utopian.

Re-emphasising an important point identified on the first day, Dr Greengross said there were a lot of people in residential care who were lethargic, depressed and unhappy because they felt themselves to be the subject of other peoples' whims. The very act of going into a residential setting itself might be a watershed and reasonable cause for depression. But she felt a real difficulty was that staff rationalise away residents' depression instead of facing it. Distinguishing between the different types of depression was important. People didn't need just to suffer it because they could be helped by a variety of treatments.

The privacy issue identified on the first day as an especially sensitive area for residents came into sharp focus. Any review really should be initiated by residents themselves if residential homes were being run to the ethos of letting people run their own lives and make decisions. But the question of who actually should do the review was more complicated. Residents may not want to confide in staff that they see every day. It may be best to look to a sympathetic stranger. Who should this be? A social worker, counsellor or therapist?

Video 'Home From Home'

The candid video of residents giving their views on residential care was then shown. Wendy Greengross said she had been a bit concerned about showing it at the first workshop. She reminded participants that the film was merely a vehicle. Whilst no-one would want to attack an individual unit, equally she did not think we should pretend that some of the things that residents said in the film did not apply to those present.

If the quality of living was to be improved all workers in long-stay care needed to ask themselves some uncomfortable questions. How do you treat a resident in an individual way? How do you help them to achieve their aspirations or goals? The things being said in the film applied to all our establishments and so how were we going to change them? asked Dr Greengross.

Most of the residents in the film (made by the Bristol Arts Project team and quoted extensively in the report of the first workshop) suffer from multiple sclerosis and paralysis from various causes. The film is a tribute both to the honesty of its makers and to the staff of the hospital unit who agreed that it should be made.

Living in a country where we all pay lip service to democracy, perhaps the most shocking aspect of the film was the residents' fears about what would happen if they spoke out. A brief introduction, prepared by students of the Bristol Arts Project who made the film with researcher Pauline Tilley-Moxon, put the problem matter-of-factly, 'Although anxious to express their views to a wider audience they are anxious about repercussions'.

The issue of repercussions or sanctions was a difficult one to confront. One of the residents on the video pinpointed it simply 'The people in a normal hospital ward go home after a few weeks so it doesn't matter what they say'. For the disabled person it is much more difficult. They were there for 24 hours a day, for ever, as they perceived it.

A ward sister, less than happy with her unit's isolated location, commented that she herself had many times overheard similar complaints to those on the video. She felt it was healing for all concerned to get these matters out in the open and cut them down to size. She remarked that at home your own lives don't always go smoothly and people in a family can have moods and sometimes take it out on one another. But with tolerance a lot of this can be solved.

In the discussion this point was built-on by several speakers. A counsellor said she believed many present would acknowledge that they had heard some of the criticisms sometimes before. She told the workshop that residents wanted to be valued for themselves and for what they were before, as well as what they were now. Residents needed to take over as much of the decision-making as possible. She instanced replying to invitations and correspondence and deciding about visitors. Reviews should be done in co-operation with residents. They must not be done behind closed doors by a group of people making decisions over other peoples' heads.

Several disabled participants reinforced this point. They did resent control over their own lives being taken from them. They argued that if an environment were set up where the disabled could run their own affairs much of the need for review would disappear because people would not feel so hemmed-in.

Some participants believed the people in the video were 'talking with great restraint' out of consideration for the feelings of staff. An officer in charge of a training centre, threw this aspect into sharp relief. Why were these residents suffocated by the people trying to care for them she asked? Why don't they take the initiative themselves and organise building of their own homes exactly the way that they want so that they could live as they wanted as individuals.

Hampden Inskip, a Cheshire Homes Trustee, replied that some residents of the Cheshire Homes had been made aware that there was money available for this purpose. But it required tremendous effort and confidence to grasp the reality. Wendy Greengross felt that this was a matter of time. People needed to be prepared for the next stage. But it was important for them to be encouraged to do so for the sake of their own personal development.

A disabled postgraduate student identified the real barrier. The offer to build their own homes might be on the table in bricks and mortar terms, but the stark reality was that there was still not a full-time support service for disabled people who would prefer to manage their own lives.

A consultant in rheumatology and rehabilitation agreed that the lack of support in the community was the intractable problem. There was a hugh assessment gap and if people wished to lead more independent lives, in their own homes, there was usually a need for much more help. He felt they needed to start reviews much further back if they were to give individuals appropriate help. There needed to be much more co-ordination and planning and it should no longer be policy for YDU's to be sited on hospital campuses. Much of the problems were due to a really severe lack of suitable rehabilitation services. You had to look at what the person wanted. Needs may be more objective, but what we should be dealing with was what people wanted.

There was also the practical difficulty of trying to make each new wave of medical students aware of the problems. His department had run a teaching scheme with a local voluntary home. But they had to stop it because they were sending so many students that the demands became too great for residents and staff.

Wendy Greengross said that it was the hopelessness and helplessness of all the residents in the film which shocked her greatly. Whilst none of us may actually ever reach our full potential, we should at least be helped to grow. The area of personal development of residents was crucial.

Why Do We Need Reviews? Who Benefits?

Dick Bailey, superintendent of Islington's hostel at King Henry's Walk, urged carers in long-stay units and homes to be very sure of their aims. He argued that they shouldn't be maintaining the status quo, but freeing residents from society's preconceptions of what disablement was. It was imperative to provide the service and resources which enabled them to achieve as much as they wished to.

Building on points that emerged at the first workshop, Dick Bailey emphasised that the way the King Henry's Walk community was run was not a panacea. It was not necessarily a model of what other people might want. In the end maximum local flexibility, backed by adequate resources of funding and staff, was the crucial factor if disabled people were to gain self-determination.

Urging participants to take a positive view of reviews, he said residents might be worried at first because they equated review with value judgement. But it didn't take long for them to accept the idea of review if it was a routine part of the way the community runs. There would probably always be a few residents who would be made specially anxious by the idea. Essentially, this was because some residents wanted to avoid life changing at all and did not want to confront their feelings.

It was important to be positive for the majority and help them to extend their vision of what was possible. He illustrated the strength this gave to individuals, and in turn, to the community, by quoting an example of a resident setting the pace.

It was the tenet of the King Henry's Walk work-style that every resident should be encouraged to cope by setting up and participating in reviews. In this instance the resident called for a senior manager from the social services department to be present at the review. The resident then explained firmly how he was not able to carry out certain tangible aims because the department was not making available enough finance for helpers. The outcome in this case was highly successful. The manager was convinced and fought for the resources. The resident was able to go ahead with his plans. The disabled person had the satisfaction of achieving results and was able to get on with life on his own terms.

Dick Bailey believed reviews had an important practical part to play when residents had problems in addition to their disablement. The King Henry's Walk team used review as a working tool with a young alcoholic resident and agreed a contract. Residents such as this, with extra problems, had expressed the need for boundaries to be agreed.

Who Does Reviews and When Are They Done?

Giving an overview of a research survey of long-stay homes and units in different parts of the country, Hazel Canter, from the Department of Health and Social Security, expanded upon a number of points that emerged at the first workshop. Some units really did need to look outwards a lot more and bring in expertise, which, paradoxically, could often be found quite close-by. At a practical level, for example, this was true of feeding problems.

The researchers were troubled by the lack of life plans and the aimlessness of so many of the residents interviewed. It was fair to say that the vast bulk of the staff concerned themselves almost entirely with physical care. Although this basic care was fulfilling a need, it was clear from deeper conversations with senior staff particularly, that they felt that residents did have other needs and that these were not being met. In organisational terms and within peoples' work priorities, the plain fact was that this aspect was missed out in the rush to get through the workload.

The researchers identified the lack of a system to look constructively at the wealth of information that does exist - but which was never crystallised, or used as a basis for action.

Pre-admission assessment appeared to be the only review that most residents in long-stay care ever had. The implications were serious because the bulk of residents came from hospital units or other residential provision and were faced, therefore, with a 'life sentence' of environment and conditions that they would not have chosen. It was an uncomfortable truth that only half the residents in the survey had had an opportunity to look over the home before going there. On the other hand 80% of the staff did get a chance to look over the unit before going to work there. In Health Authority provision, there was less likelihood of both residents and staff being able to look around the unit before going to live or work there.

If there was to be change in the dynamics of long-stay care it meant there would have to be concentrated and continuing attention paid to the question of staff communications. This applied to communications within and outside the unit or home and across the administrative and professional boundaries. Too frequently the researchers found staff would work against the plans of other staff e.g. dressing a resident and keeping up dependence when the goal was for that person to be prepared for living alone in their own home.

Mis-match was another minefield for residents, as well as staff, Hazel Canter told the workshop. She illustrated this by the case discovered by the survey where residents in a unit were being re-abled for maximum independence. Unfortunately, there was no suitable accommodation for them to move on to for leading their own lives so morale had sunk all round. In contrast, at another home, staff went and kicked-up such a fuss with the local housing department that officials agreed to make a regular allocation to disabled people so that they could move on from residential care back into the community.

Often it really did need a tough-minded approach to see things holistically, then to press for action said Hazel Canter. She believed this to be an essential part of improving the quality of life for long-stay residents and review could play an important part in achieving these goals.

General Discussion

In the discussion there was widespread support for the concepts of review and life plans. Speakers argued for flexibility and for objective outsiders to be asked to help staff and residents with review. Several speakers welcomed the idea as 'a good preventive device' which would help to avoid crises. Many participants argued for a formal system of review as this would be the best protection against good intentions being forced to one side by the day-to-day pressures of coping. There was also much support for the idea of residents having more control of their own lives and having 'safe space' in which they could express their feelings freely. As one participant put it, 'keeping accumulated tensions bottled up 24 hours a day can make people ill as well as being disabled'.

After the workshop groups had hammered out aspects ranging from the 'gratitude barrier' to the need for the sympathetic stranger to be more than just a father confessor because residents would want outcome and action not just to unburden themselves, they reported back.

The concensus was that review was essential. They should not be rigid or formal but needed to be built-in to every establishment's routine running. They needed to be done regularly but the frequency should take account of individual's requirements. Some of the factors to be taken into account included age, degree of dependency, and the person's wishes and goals. They must result in action and should be considered a self-learning process for staff as well as residents.

Those residents present emphasised that the real issue underlying the day was: 'The powerful and the powerless'.

It was a point well taken by the Chairman, Malcolm Johnson, bringing the workshop to a close. 'If we are to get rid of paternalism in social welfare then reviews and risk-taking are the catalysts', he told participants.