**Leonard Cheshire Resonate Project**

File Title: The Home. GLC answering the question 'What is a Home'

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Start of Transcription

00:01 to 00:09: Man: Roll 1, Scene 1, Take 1, Leonard Cheshire. *Indistinct sounds, and* *Sound of a clapper board.*

00:10: GLC: What I want to do is to try and answer the question 'What is a home?', because I find that when I've been speaking to people, they'll say to me 'Yes, I understand what you said about your philosophy. I understand that what you're trying to do is give disabled people a normal life, but I can't really picture a home.' So, I would to try, as it were, to take you into a home, show you something of its life and just what goes on. My difficulty is we have quite a large number of homes, and they are all different. In fact, we cannot say that there is such a thing as a typical home. Our policy has always been to allow local groups - who want to start a home - the maximum possible freedom, almost autonomy, to do it in their own way. To decide what they think is the greatest need, and to meet that need in their own way, according to their own local circumstances. And obviously, those local circumstances, in addition to their particular customs and traditions and culture and so on, will govern to a large extent the form that the home takes.

(1:35) So that we cannot say either there's a typical home or that in our own mind there is such a thing as an ideal home, because we are dealing with people, human beings, and what may be objectively speaking an ideal home may not suit a group of particular human beings. So, one has to remember that. What I think I would do is to take one specific home and one particular disabled resident, and in talking about them, use that as a basis to try and give a broader, and a more comprehensive account of a home.

(2:28) Now, I think I have to start by one or two things in general. First, what are the homes for? Who are they for? And what are they trying to achieve? Well, they have been brought into being solely in order to feel a gap. We only exist if there's a gap to be filled, but nobody else is filling it properly. And the particular gap that we stumbled across, was the need for the right kind of accommodation for physically disabled people who are disabled beyond the point where they can live their own independent lives, in a community, on their own or with their families. They need some kind of -if I can use this word- sheltered environment, and they need a degree of care in the form of human help by staff, and aids and gadgets which would not be available as things stand today out in the world.

(3:43) Now, these residents, as we call them, vary in age very considerably. The youngest may be 16-17, and the oldest may be right up to the 70s or 80s. But by and large, we concentrate on the younger, because we find that particularly amongst the younger age group, there is a real need for the right kind of environment. An environment that will enable them each to grow and develop in the way that he or she wants, within the limit of their disability. I think we want, first of all, to give them the feeling of security: 'This is my home, my home, I have a right to be here, and within reason I can do what I like in it. If I go away and try to experiment with living on my own, and I find it doesn't work, I can come back.' Because I feel that basically every human being in the world needs the security of a home that is his own. So this is the first thing, of the homes that we try to provide.

(5:06) But secondly, they're trying to give each person the maximum possible choice of the type of life he wants to live, to express himself in his own way, to help him to be a creative, useful member of the community. In other words, to help him do some work, or follow a hobby, whatever he wants. In many cases, they decide to get married, if they do, we'll provide a married accommodation and the care that they need.

As to the homes themselves, the actual buildings and facilities and so on that they have, these obviously vary very greatly. Ideally speaking, one would like a purpose-built home, that is to say a home specially designed and specially built from scratch for the disabled people who are going to live in it. But the problem is, to do that, you got to have all the money in the beginning. Most groups, most communities, can't afford it. So, a great many had to start with existing buildings, some of which are not really suitable, they have been able to adapt them, then eventually extend them, perhaps to the point where in the end, all the residents are living in new extensions, and the original building is used for staff quarters and recreational workshop and so on.

(6:41) One advantage though that an old home has, if it's the right home, is that it does have an atmosphere of its own, it comes from the people who've lived in it. And that atmosphere will be a real contribution, I find, to the life of those who live in it.

Now finally, before I come to the one home, I'd like to mention one phenomenon that I've noticed, it always strikes me, and that is that, although every home is there to give the individual residents a life of their own, in fact, as it develops, it begins to acquire a personality all of its own. In fact, if I can put it this way, standing a little back from it as I do -I'm not intimately involved in administration- I see each of a different home rather as different individuals. They do have an individual personality and character of their own, but of course the same nature, they are all basically the same in nature.

(7:55) I think the reason is, the amount of effort that's gone into building that home, and getting it going, because after all when you consider that every home has had to start absolutely from scratch, in a new district, probably unknown, with no resources, and so a whole mass of people, young, old, from different backgrounds, have joined together, to collect money, to work, to design, to plan, to organise a home. And each of them in their little way, or their big way, has left a little bit of themselves in their home. And so have the residents, so that you find that the residents, while completely leading their own lives as they want, are also part and parcel of something bigger than themselves, to which they themselves contribute and from which, obviously, they draw strength and support.

(8:58) And it's very interesting, I find, to get one resident from one home goes to another for holiday. He comes back and he says 'That was a beautiful home. It was a marvellous home. But how glad I am to be back here.' Now, the residents in the other home cannot understand this, because to them, their home is the best. And it may well be that the other home is a better home, but to the resident himself, his own home is 'my home, and my home is where I want to be'. And I don't think I've ever heard somebody go to another home, and come back say 'I wish I was there'.

(9:41) Well, now to come to the one home that I'd like to describe, Timsbury, the home near Bath.

Thank you (*sotto voce*).

10:02: Man: Take 2, take 2. *Indistinct sounds, and sound of a clapper board*.

10:10: GLC: Well now to come to my one home, a home called Timsbury, near Bath, in the West Country, in Somerset. It started in 1962, in an existing building which I thought was a most unlikely, most unlikely, building for a home, in rather hilly country and rather remote. When I went down there for the first time to see it, I thought 'I don't really know how this will work out'. They started with 5 residents and by 1977, they got to 31 residents, with 2 holiday beds. They had given 40 single rooms, and they had a workshop, and a physiotherapy room, and a nice communal room, and a television room. So, then it's become a very nice building.

(11:04) The residents, of the 31 they have, 60% need help with getting up, 80% need help with bathing in one way or another, and 30% are incontinent; 6 of them all together are

ambulant, able to walk, all the others are in wheelchairs. So, in fact, the home makes a great effort to get those who can out of their wheelchairs for part of the day. And there's a

great emphasis on physiotherapy, on that, on getting them out of their wheelchairs.

(11:41) Just to give you some idea of their daily routine, because I don't think that most people appreciate just how much effort for a severely disabled person goes into the sheer basic functions of daily life of getting up, being bathed, going to the toilet, having a meal and so on. And for many of them that really takes all their efforts, and the rest of time they just want to sit back and relax.

(12:20) As to their routine, its starts for some them at 6 in the morning, that's very early but in fact, it's by their choice. This is 2 or 3 of the ambulant ones who can get up themselves, they get up at 6. For the rest, getting up starts at half past 7, and will go on till about half past 9. Breakfast starts at quarter past 8 and goes on till about 9, which means that those who can't get down in time are given breakfast on a tray in bed, very nice. Then bathing, well bathing is a long operation, when most can only be taken in a hoist or lifted into the bath, thus it cannot be done first thing in the morning and last thing at night, but stretches throughout the day, and people have to take their turns. Then mealtime, they have a very nice dining room, and they sit at tables of 4, trying to get 2 wheelchairs and 2 who are not in wheelchairs, and quite a number of them will help each other if they can't manage to feed themselves. Physiotherapy is a crucial part of the day, and there are 2 part-time physiotherapists who come to the home and give physiotherapy to those who are going to benefit from it. But it is most important, if one is a disabled person, to do everything possible to keep mobility, keep as active as possible.

(13:50) The doctor doesn't have to come very often because most people have got to the point where, unless they catch a cold or get pneumonia or something, there's nothing much more the doctor can do. So he comes round once a week, on a sort of weekly routine visit, and always on call when needed.

(14:08) But then the final part of the routine, the most disputed of all, is going to bed. And this is an issue with all the homes, all over the country, and I don't think it will ever get totally resolved. You can see the problem, but each individual wants to go to bed at the time of his choosing, and that's going to vary day to day and according to circumstances, has he gone out late? Is there something on telly he wants to watch? And so on. But as 60% need help with getting to bed, there's got to be the staff there, and not many are going to want to go to bed before 8, so that means the night staff has got to do it all. Well, if you have a small home, you can't afford to carry more than 1 night there, it's economically impossible.

(15:02) And the bigger homes like Timsbury will have 2 or, if they possibly can, 3 every night in order to allow everybody to go to bed just when he wants. And this is the policy of their home, in fact of every home.

(15:19) Now, something about their leisure and their recreation. But Timsbury home is remarkable for the degree of involvement that it's got with the outside community. You get an enormous number of outside visitors and outside voluntary helpers; and many of them are very young, they are children, they are between 8 and 10, a great many of them. And it really is a most inspiring sight to come into the home and see them. What is absolutely remarkable there, and the most meaningful thing of all, I think, is that the children never notice the handicap, they're just interested in the person, and they'll come and write letters or read, or bring their comics and show their comics, or just be there and just let it be part of their own day spent with the residents. Others, like the local ATC squadron, that's the air training corps, have adopted the home, and they come and do work and projects and so on.

(16:28) Then as I'm sure you can imagine, if you live in a home, the one thing you want to do, that most people want to do, is to go out. Now there are some who find it much and they don't, but the majority do. And when they go out, they don't normally want to go out on a group expedition, they don't really want to be herded round where you or I want to take them. So what they like is a private group, and so local visitors will come along, take somebody out in their car to go shopping, or to go and watch a football match, some go swimming to the local swimming-bath. Of course, Timbury is not lucky like some other homes which have their own swimming-pool in the home itself. And that is used not only for the residents in the home, but other disabled people who live in the district, and they keep come in like the Spastic Society, the Multiple Sclerosis Society, the Red Cross and so on, they're all coming. And that's a very active part of the home – the swimming-pool.

(17:44) Timsbury is unique in 2 respects. It has its own chess-club which is very popular, and other people come in regularly and are members of the chess-club, and they play chess. They also have their own W.I. as we call it, The Women's Institute, and that meets at the home, and has outside members who come and take part in the meetings. The residents go out of their way to be helpful in the home, that is to say they lay the tables for all the meals, and whenever there is a meeting they prepare the room for the meeting. By and large, I think I can say that doing household chores is not very popular in the home, the homes tend to think that there's staff to do this, and that it's not their own job. So Timsbury perhaps is an exception.

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18:35) It also has its workshop where, amongst other things, it does pottery. Pottery is very peaceful, and I think it's very popular. But its workshop is not as big or as varied as some of the workshops throughout the homes, and if you go to some of the bigger workshops I find it really inspiring to walk around and just watch what they're doing. What some do with such disablement is able to make.

(19:10) Timsbury is different in another way, it has its own garden area and greenhouse. And one finds that disabled people, a lot of them, love gardening, provided you have a raised garden-area that they can work in. And also, it has a day centre, which means that other disabled people from roundabout come and share their life. And in their future plans, which are now in the course of active preparation, not only are they extending to give every single person a single room, but they are going to build a separate large day centre which can really help the neighbourhood. And therefore, you can see this 2 way coming and going between the outside and the inside of the home, which means that the home is integrated into the community, and those who live in it themselves feel that they are integrated.

20:13 to 20:25: *some indistinct sounds in the background*.

20:29: GLS: Another activity of the residents which really affects the most fundamental issue is that of involvement in decision-making in the home. We have, at Timsbury, one resident sits on the assessment committee which is in effect the admission committee for the residents, and another sits on the committee that appoints the staff. And when you think that most homes have a ratio of at least 2 staff to 3 residents, and some time 1 to 1, because of the degree of disablement, you realise that appointment of staff is a crucial thing to those who live in the home, like having the right staff, everything hinges upon having the right staff. The whole question of involvement by residents in decision-making is one of, I think, the most important and fundamental of all, it's absolutely essential that those who live in the home, the residents, are really consulted, and really have a say in all the decisions that affect their lives. This is agreed, I think, completely in principles, but of course is left to each home to decide how it's going to put it into practice. But what we are basically aiming at, is one family, not 'we the staff, you the residents', 'we the management, you the staff' and so on, but one, united, integrated -if I may use the word- family.

(22:03) And now to take just one resident, my one chosen resident, Norman Whiteley, who's at our London home, or rather the first London home that we built. At the age of 14½ when he was at school, he was going to school prayers, and he slipped on a little bit of ice that he didn't see, he fell over backwards. Nobody thought very much of it, although in fact he had cracked 2 bones at the top of his spine, basically his neck. And he walked about like that for nearly a year till they discovered what the trouble was. He was rushed to hospital and operated on, and something went wrong with the operation. The consequence of which, the bone, something happened to the bone, and pressed on the nerve, on his spine, so that he is as you see him now, really very paralysed indeed. And Norman spent a long time in hospital, at the moment that this home was opened and he heard about it; and it was decided that it would be better for him to come out of a hospital institutional environment to this particular home. But curiously, Norman was very apprehensive, and this is another rather remarkable thing you discover that somebody who's been in hospital for a long time, may well fear the step-out into the outside world. He's so used to being protected, he suddenly thinks 'This unknown, what am I going to?' And this is when Norman arrived at the Dulwich home. Well, gradually he had to find his feet, and this, of course, he did because he is a man with extraordinary initiative and highly intelligent. And one of the things that he contributed to was a minor revolution in the O.T. section, in the occupation therapy section. They'd been making basket and wickerwork, and the usual things you see everywhere, and suddenly one day - I suspect largely prompted by Norman- they said 'We've had enough of this, it reminds us of hospital'. They threw it all out of the window, literally out of the window. So then they had to start again, with different activities, and together with various others, Norman started a printing press. It all sort seemed to fall out of the sky, it just happened. It started by proof reading, discovered those who in need of printing in the area, got an order from a local rotary club, completed the order, and they've been working ever since doing their printing. And then the next thing that Norman did, when the Disabled Person Act was passed in Britain, emphasizing the need for integrating the disabled into a normal living, Norman got elected onto the local council, and he's a full voting member, and he goes there 2 or 3 times a month, being particularly interested in the committee on old people, disability, and health.

(25:17) But finally, and what to him is the most important of all in his job is his wheelchair fund. Entirely by his own efforts, he has created and built up a wheelchair fund to raise money, to buy wheelchairs and send them overseas to the developing countries, where usually they have no wheelchairs of any adequate quality at all. He discovered this need when he attended the first international conference that we ever had in 1969, when listening to the various speeches, and I suspect meeting the delegates in between, he discovered this need. And gradually, he's built it up. He raises money in many different ways, by selling badges that are very popular at schools, by selling emblems, by going out and giving talks in different places, but there's one particular way in which he raises money and that is by organising a carol service at Waterloo Station in London, just before Christmas. He's got a local school that comes along with a band and they play, Norman is there in his wheelchair and he usually brings 1 or 2 others to help him, and all sorts of children go round with their collecting boxes waiving them in front of people, and it is always a great success.

(26:52) To me it's symbolic, because it shows that everyone of us, as a human being, wants to feel that we can be useful and contribute something. And I find that when a home gets onto its feet, when it got over its great struggle to get onto its feet, it's there, then it begins to think 'What can I do for other people'. So today the homes are beginning to reach out to see what they can do for other people in need, either in their immediate vicinity or further afield. And Norman is a symbol of this, that he now spends his life building out something that he hopes and feels is going to do some good, in his little way, to the poorer countries. (27:44) And I feel in my heart that this little wheelchair fund that started so modestly, will build up into something really worthwhile...(27:54) *[addressing someone in the background]* Finished now?

27:58 to 28:08: Man: … Take 3. S*ound of clapper board*.

28:14: GLC: Now to come to the one resident, Norman Whiteley, who's in Dulwich, our London home. When he was 14 at school, he was going to evening prayers, he slipped on a bit of ice and fell on his back. I don't think anybody quite realised how serious the damage was so instead of leaving him, they helped him up, with the result that he's disabled now as you see him today, very heavily disabled. He's spent a long time in hospital, and also went to one of the best rehabilitation units in the country, before he was sent to Dulwich. Now the curious thing, although he'd been in what wasn't really not the best place to be, in a hospital, and heard he was going to a home, he didn't know much about, he became very apprehensive. And I have find it in other people who got used to the protected life of a hospital, the thought of suddenly going out into the outside world can be quite frightening, I think it's something you don't know what you're going to. So when Norman arrived at Dulwich, he had to find his feet. The home was only at the beginning, had only 5 or 6 residents, still decorating and building and everything, and the idea behind the policy of admissions was that they were going to take actively minded residents, all of them to contribute something towards the home. (29:39) They were to do the washing-up, the household chores and so on. It worked till they got about 8, then, of course, it broke down because there was too much work to be done. But they were all actively minded residents, and they wanted to move forward. And one day, there was a minor revolution in the O.T. room, and they threw out of the window, almost literally, the basket work and the trays, and the usual things you do in hospital, they didn't want to have any more to do with that. In its place, Norman, 1 or 2 others, started a printing press, it all arose from a sudden unexpected need of the local rotary club. And from that little beginning, they built up what was a very effective printing press. In addition to that, Norman is on the residents' committee, because every home has a residents' committee for the reason, obviously, that it is absolutely vital to have involvement by residents into decision-making regarding their home, and each home has to work it out in the best way they can.

(30:44) He's a member of the local council, full voting member, a borough council, and he goes out 2 or 3 times a month to that. And finally, what to him is the sort of peak of his work, his career, a thing that he set his heart on is his wheelchair fund. He decided that he wanted to do something for the poorer countries, and he discovered that in the developing countries there are practically in our homes no wheelchairs, no proper wheelchairs. And so he goes round, giving talks, he sells badges that are very popular to schools, he sells key rings, all sorts of little things he sells, in order to raise what is now over £3,000 a year to buy these wheelchairs.

(31:39) He's a symbol to me of somebody, who having found his own feet in a home, is now looking out and wants to do something for other people. And Norman's special way, every year, of contributing to this fund, is a carol service that he organises at Waterloo Station, a day or two before Christmas. He's got a local school that provides a band, he goes there and takes charge, gets all sort of young people with tins, and always, it's not only a great success, but a very happy occasion. And I know that deep in Norman's heart, is the hope that out of this very small beginning, will ultimately come something that is really worthwhile, that is making quite a big contribution to the developing countries. That's his dream.

32:40 to 32:48: *at first silence and then* Man: ...Take 4, *and the sound of a clapper board*.

32:53: GLC: And now to come to the one individual resident, Norman Whiteley, who's in Dulwich, our London home. He was at school at the age of 14 when going to the evening prayers (chapel), one night, he slipped on a bit of ice and fell over backwards. I don't think anybody quite realised how much damage had been done, it would have been better if they had left him, instead they helped him to get up so now he's disabled as you see he is, very disabled. He spent a long time in hospital before he came to the home, and when he heard he was coming to the home, he was rather apprehensive. I think he got so used to the secure atmosphere of the hospital that he was a little afraid of the unknown. The home itself at the beginning, there were only 5 or 6 residents, decorating was still going on, they were experimenting with getting only residents who were active and mentally alert, and could help in the home. So the home too was finding its feet. Well after a bit, Norman was elected onto the residents' committee, that meant that he was one of the people who had contact with the management committee on decisions, and it obviously is very important that, those who live in the home, the residents, should always be consulted about anything that affects their lives. And every home has to work out the best way of doing it. There was a minor revolution one day, in the O.T. section, they got fed up with the trays, the baskets, the usual things that you make in hospitals, threw them right out, and started from scratch; and together with a few others, Norman started a printing press. And it's gone from strength to strength. He also is a member of the local borough council, full voting member, and he goes there 2 or 3 times a month. But most of all, from his point of view, he started a wheelchair fund, his own wheelchair fund, which means that he raises money to buy wheelchairs for our homes in the developing countries, cause he discovered that in those developing countries there are virtually no wheelchairs at all, so it's a very valuable thing to them. He sells little tags, key rings and badges which are quite popular amongst schools. But his main way of raising the money, is a carol concert that he organises very year, 2 or 3 days before Christmas, at Waterloo Station in London. He's managed to get a local school to provide a band, he's there in his wheelchair taking charge, there are all sorts of people going round with tins, collecting tins, and it really is always a very happy, a very successful occasion. And Norman, deep in his heart, I know, hopes that out of that small beginning, will grow something bigger and bigger, in terms of giving to the developing world.

This is his great dream.

36:04: Speech Ends

36:13: *Indistinct sounds, and* *sound of clapper board*.

36:20: End of recording

End of Transcription