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Session 8  
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## Where And How Do People Want to Live?

When I was a little boy, I lived many places. My father's work took him to different countries, to the remotest villages, sometimes to big cities, but always to a different house. I lived in a two-room home in the wilderness with my parents, a brother and sister. I had a friend who was the cook for the construction crew my father was in charge of. This cook was a Chinese man who spoke little English, but who looked after me whenever he could. We were good friends.

When we moved to the city, we lived in another house. I remember that my father began to prepare land for a new house he would build for my mother and sister and me. I roasted potatoes in the fire we built to burn the tree stumps. I remember that it was a bigger house than any we had lived in before. Best of all, it was *our* house. I remember that I had to carry much wood to burn in the furnace so that we would be warm. I didn't like to do that—but what I liked best of all was a room of my own. It was on the upper floor and had a large window. I could see across the street and over the rooftops to where my friends lived. Best of all,

could have my own radio to listen to during the day and even at night if I kept the sound low so my parents wouldn't hear. My father decided, when I was 12, that I could even paint the room my favorite colors. I decided on green walls with black trim. Everything was green and black. I loved that old house. I liked it even better when we changed to an oil furnace and I didn't have to carry wood. And I liked it because my mother bought us a piano and we could play anything we wanted to.

I guess when we ask "Where and how do people want to live?", many of you have fond memories, as I have, of how our own lives have been lived and the places we have lived in. I am sure there are some of you who haven't shared the kinds of joy I have about the places you've lived and the life you've had. But you have, I am sure, some ideas about what your dreams have outlined for you.

As a practicing Architect, I have derived great joy from the process of molding the ideas and ideals of clients into the fabric of a place to *live*. *Each house a special* place to live, conceived of ideas-whose goal is the molding of children into adults and the fulfillment of happy hours spent in what we call "Living"; a place where people can be a part of a family, part of society, a place where people can not only live happily, but where they can become meaningful persons.

Surely "Living" in its context means something different in terms of environment to someone who lives in a thatched house in New Guinea or Kenya, or a mud house in Peru or Libya, or a brick house in Denmark or a wood house in Canada. But the concept of being able to live in an environment which can be called "home" is the same for us all.

In 1966, when the first International Working Conference on Architecture in Mental Retardation was held in Copenhagen, Denmark, I recall how dynamic the exchange of ideas was. Architects and planners from 7 countries were enthusiastically sharing concepts on how to humanize the designs of institutions for the Mentally Handicapped. And even at that meeting, we were asking ourselves as designers, "Where do these people want to live?", "What is best for them?". Incredibly, there were few, if any, who could honestly say "I asked the retarded people and they told me." We, as designers and planners, were still telling ourselves "We know what's best for them and they don't. Even if we provide what they say they'd like, they won't take care of it and will probably destroy it." The result in many instances was design which was resistant to human imprint. Designs which were and

are impersonal, impervious and inorganic. Society's "put away" system and its disgraceful architecture and environments can still be seen and deplored around the world, but a new era is here. If there is one lesson and one alone, that I could offer to countries who are looking for ways to improve the life style of their mentally and physically handicapped, it is to learn of an profit by the evolution

error; and to take advantage of the immense progress. For the sake of all handicapped persons don't attempt to create an institutional system where none exists. Develop a system wherein the handicapped can "live" like you and

The enormous contribution the Scandinavian societies made to us as a result of their pioneering the humanizing of environments for their handicapped institutionalized people, has had an even more far-reaching impact than they dreamed possible, I'm sure. Their efforts taught us that yes, indeed, mentally retarded persons could live the same way as normal people, but also and most significantly, their experiences showed that many mentally handicapped people who had severe mental or physical or behavioral problems, dramatically changed and improved when given the opportunity to share a more normal kind of life in normal surroundings. It seems that evidence now supports the concept that the more severe the handicap, the better the chance for improvement if the "living" environment more closely approaches that of the conventional family "house". There have been a number of studies conducted in the U.S. of people living in small residences in the community-people who formerly lived in institutions. These studies are amazingly consistent in one result-they show that a very large majority of these persons (in excess of 80%) not only show improvement in capability, but are exceeding the plateaus of learning previously thought to be their maximums. This is attributable, of course, to the total change in life style and environment both in and out of the home, but substantial credit must be given to that environment in which they "live".

We speak of normalization and of normalizing the environment. and of creating opportunities for the retarded person to live in a local community of his own choice, and of his rights to live in a home of his own choice. We talk of the advantages to the retarded person to live in his family home as long as he can, and we eventually talk about what should happen if he cannot or should not live any longer in his or her family home. We have a pretty

good idea of what works best as an alternative and of the type of environment which will be best suited to his needs, to suit his progress toward fulfilling a reasonable life style commensurate with his legal and moral rights, one which will further his or her acceptance into the mainstream of society. But the problems are much more complex than that.

Yes, I can design a home for a family to suit their needs. I can spend time with the parents and children, listening to how they live and how they want to live. I can hear them describe to me rooms, spaces, materials, colors, textures that they have seen which please them. I can present sketches and models and samples of materials to explain the sketches in a manner designed to answer the family's desires and needs as they express them to me. Because of tradition and experience, I know what will be successful for many persons, and I am able to weld all the ideas together into a distinctive building. In the process, I am providing for the interchange of expression between different personalities.

But designing for people who have been institutionalized at some time, or for whom an abnormal amount of physical care and help is necessary, or who must leave their family home early in life, or who must, upon achieving adulthood, live in a protective family setting, the problems are different and more complex. Not more complex because of the specific answers to particular problems or needs, but more complex because of the need to normalize and personalize spaces for individuals and groups whose composition is neither normal or in some sense personal.

To design meaningful environments for many mentally handicapped persons, particularly the severely handicapped and most of those who have been institutionalized, I must rely on my own judgment and on the wisdom of those who will assume the managerial role for them| these people either cannot effectively speak for themselves, or they have lived in restricted environment for long periods of time and cannot offer constructive help because of their lack of exposure to the alternatives. For these people, it not only helps, but it is vital for the designer to have experience in meeting their special physical needs, and also, to have the moral responsibility to act as the advocate for the handicapped person. Invariably, designs reflect these qualities and abilities. I can tell in a minute from looking at designs whether or not the designer is concerned

about the needs of the individuals who will live therein or whether he is responsive only to the need to reflect a better life style than the institution.

Those retarded who have been asked, and who have some exposure and experience in living outside of institutions have made many straightforward comments, such as: I want to be where there are choices-noone asked me what I wanted before .I'd like to be close to work. I'd like to be close to my girl friend/The.vast majoritysay I'd like my own room with my own things. Some say: I'd like to lock my own door.

Mentally handicapped people are like other people-they have their specific likes and dislikes. They have preferences about many things, where they want to live, what they want to do,what they want to eat. Most have not had the chance to enjoy many options. I'm sure that many haven't ever roasted a potato in a stump. Many need company as security around the clock, although most prefer the privacy of ownership of their own room-provided that it is, indeed a private refuge. Many are still hesitant about sexual closeness, many are hesitant to accept the normalization of their life styles or environments; it is because their experiences are limited. I recall a transitional residence we designed as a training house for those who could leave an institution to eventually live in a house in the community. We designed single and double rooms. In the single rooms, the bed was in a corner against two walls-leaving the center of the room open for ease of movement, for placement of furniture and for the creation of a space which could be more than a bedroom-in fact, a place to work at a desk or watch TV or play music or entertain a friend. Many *new* residents in this building could not stand to have the bed in the corner because in the institution, it stood out from the wall, in the middle of the room and they were not comfortable with it any other way.

Most retarded children and adults want to be like other people-they want to overcome their institutional hang-ups, fears and hates. They want to overcome their unusual actions and appearances, and they want to be part of their peer group.

We know from long experimentation that normalization and integration into the mainstream of society go hand in hand. It just isn'tnormal to build houses for larger groups than one normally finds in a given neighbourhood. The size would be inconsistent with the neighbourhood, and the group reaction would not be typically family-oriented. We also know from experience and

experimentation that the developmental progress of handicapped persons is most successful if groupings are kept small

We have been told that the maximum number of residents that an individual counselor or house parent can expect to handle and achieve some personal relationships with is 8. Our studies of behavior modification and personal achievement in my country seem to bear this out. This is valid only with persons of higher capability. The studies indicate that with children and with those who have more severe handicaps, the group should be smaller. The underlying incentive is that more personalized care and attention at an early age can and will offer the increased chance for improvement and hopefully, when one grows older, transfer to a more conventional model. Certainly no *one* model can be considered ideal for all persons and purposes. We know that the mentally retarded person, just like his normal counterpart, has the need to change his environment and his life style as he grows older. His physical needs will change, and his house should change to suit his needs-just as they do for you and me. This suggests, of course, that every society must have a series of home environments suitable for different ages of life, and for different kinds of people. Where and when possible, the mentally retarded person should have the right to choose from these options.

We must always remember that for the mentally retarded person and others who are handicapped and who are dependent on society to help provide them with an acceptable life style, even the family groupings may not be achieved by choice-nor may the option to change family groups be available to him.

It is therefore incumbent on those of us who are to be his advocates, to help him find the appropriate environment best stilted to his needs and in recognition of his legal and moral rights.

What this should be and where, whether it should be new construction or renovated space is not for me to decide. As an architect, I am concerned that the environment make available to each and all, the best life style for the individual, in keeping with the norms of his own society. For small children, the need for space in which to play and learn is paramount. For those who must live in wheelchairs, other kinds of space for maneuvering and other kinds of helpful devices are in order. For young adults, spaces which encourage socialization survival skills is important .For adults, the needs change again. and are geared to the resolution of the appropriate life style. May I

quote a page from a book which I have that is entitled "If You Want To Build A House":

**Living:**

"Cooking and dining are comparatively uncomplicated. They have a beginning and an end, and can be fixed in space with no great stretch of the imagination. "Living" is another matter. It can cover quiet pursuits like reading, writing, studying, even sleeping, less quiet ones like conversation and polite music, messy ones like painting and playing and dressmaking, and noisy ones like dancing and singing and practically everything that young children think is really fun to do.

"Remember that your family is made up of highly differentiated individuals, each eager to pursue his life under the pleasantest circumstances and with a minimum of interference. This means that **the real basis for house-planning should be the individual, not the group.** The extremes to which this principle might be carried are surely no more absurd than its complete disregard in conventional practice, where everything is divided on the formal, arbitrary basis of bedrooms, dining room and living room rather than in terms of the innumerable, overlapping, often conflicting activities of each member of the family. Both the right to make noise and the right to quiet privacy should be prominently listed among the civil liberties.

"The average house is a makeshift answer. When the children are young they tend to be all over the living room, leaving a dismal wake of building blocks, sticky chairs and broken chalk. When they are older there is the problem of where they are to entertain their friends, and more often than not it is the parents who must flee to the shelter of bedrooms ill designed for refuge.

"There is not only the battle between the generations to consider, but the perennial struggle of the musical and the tone-deaf, the orderly and the disorderly, the retiring and the gregarious, and, of course, the war between men and women. Domestic stability is precarious enough without the unnecessary irritation of an unfavorable environment. The smaller the family, the easier the problem."

You may have heard comments to the effect that "If you wouldn't design it that way for yourself, don't do so for the mentally retarded"; or "The key to whether it serves the normalization concept is whether you would want to live there yourself".

These certainly are thought-provoking statements. Some years

ago in a chapter I wrote in a book about the problems of the mentally handicapped, I said:

"How can we expect our retarded, with their inability sometimes to grasp the meaning of things, to progress in an atmosphere of stagnant environment, where programs, shapes, attitudes, vistas, moods, appearances, rarely change?"

"We have yet to probe deeply into the aspects of environment not only as a useful tool in developing a full enjoyment of life but also in its potentially vital role in therapy and education of the mentally retarded. I think it is significant that architects today are themselves criticizing their profession's tendency to 'do it as it was done in the past', rather than to say 'There must be a better answer'. It is those who seek a better answer that we principally depend on for progress in the field in the years to come."

This brings me to some comments on the quality of the environment, particularly in the residential setting.

My first visit to a Danish School Home—a five-day residence for children attending a special school, was an experience I shall long remember. In contrast to the drab, monotonous environments that I had seen so often, I was confronted with a bright, gay, colorful, personalized environment. Indoor plants and flowers were everywhere. Colorful light fixtures and mobiles hung from the ceilings. Floors had carpets as well as hard surfaces. Furniture was soft and warm and comfortable, and not in the least institutional. It was indeed a happy place to live in. I still am appalled today by the bureaucratic approach to design and by the haphazard efforts of unthinking and uncaring planners and designers whose objectives are low cost, mini-institutional buildings with non-varying wall, ceiling and floor surfaces and interior furnishings and appointments designed for durability rather than comfort.

Our greatest concern at these international exchanges is that those of us who have design responsibility for the mentally handicapped and who care enough to be advocates on their behalf, can show to others not only the efficiency in what we do in terms of cost and construction, but the ultimate result in terms of greater human values.

If we can stick to the premise that it is the individual who is important—the concern about the group and society will take care of itself because each and every individual will be able to contribute to that end.