

VII. SPECIAL HOUSING NEEDS

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Norman Haw, Canadian Paraplegic Association:

I am the Director of Rehabilitation Services for the Canadian Paraplegic Association. I have been asked to speak to you today on 'special needs' housing in British Columbia.

I will give you a brief overview from my perspective as to what is taking place with regard to housing for people with special needs, some of the problems we are encountering today and the possible future direction and the challenges that will confront us all. I'd like to highlight the four areas upon which a comprehensive program of special needs housing will fall. These are: affordability, architectural access, support services, and coordination.

Affordability - for the disabled individual who may well be employed, as well as cost-effective for government and the community. Architectural access - we have many levels, but the essence is to provide a physical environment where the disabled person can function as independently as possible. Support services - to include basic homemaker services to manage household duties such as cleaning, laundry, shopping, etc., and attendant care for those who require help with bathing and other personal care tasks. Coordination - this is two-pronged, as disabled people are linked to affordable housing and both are linked to support services. As I discuss housing in British Columbia, I will be swinging back and forth from one to another of these four concepts because they are very much interrelated.

I have chosen to provide my overview of British Columbia housing from the developmental perspective, beginning in the early 1970's. Prior to 1973 there were few options open for persons requiring physically-modified living accommodation. Single family homes could be built or modified, existing rental stock could be modified if some of the basic parameters were required such as space, level of external access, or thirdly a disabled person could take up residence in some sort of an extended care facility.

At first the movement to develop specialized housing was very slow. In 1972 the first fully accessible apartment in British Columbia was the Paraplegic

Lodge built and managed by the Lions' Club and the Canadian Paraplegic Association, British Columbia Division. Because there were so few accessible apartments, the lodge was to serve as a halfway house, where disabled persons moving out of a rehabilitation centre could learn independent living skills while looking for permanent accommodation. When the lodge opened there were only minimal support services under the government-subsidized home nursing program. Therefore, the lodge could only accept disabled persons who were fairly independent and had family members to assist them with personal care. One unique feature of the lodge was that it provided some homemaking help. Most residents had sponsorship by insurance agencies or provincial government programs to pay a large per diem on their behalf.

In order to address the needs of more severely disabled people, CPA was able to convince the provincial government in 1974 to fund the first group home. Several people live together in a specially, architecturally-designed house in which homemaking tasks and personal care were provided by a full-time live-in person. This was our first effort to demonstrate to government that it was less expensive for disabled persons to live outside of institutions. There are now approximately thirty group homes operating in Greater Vancouver area and recently such homes have been physically designed to meet the specific needs of the residents.

In terms of affordability, the government has been providing a subsidized apartment complex to accommodate seniors and low income families. 1975 saw the first of these construction projects built with a percentage of wheelchair-accessible suites - this one being Steves Manor at Jericho Beach where 12 units, or 5% of suites are wheelchair accessible. Since then, 5% of suites in all provincial housing projects have been designed for wheelchair use. 1978 saw introduction of the Long Term Care program as an offshoot of British Columbia's Home Nursing program.

Long term care came into being and provided not only nursing services but personal care and homemaker services to disabled individuals living in the community. The government provided a maximum of four hours of care per day. The long term care program allowed pooling of hours by individuals, hence quadriplegics could pool attendance-care hours and share a full-time attendant outside group housing. This allowed many more disabled persons to move out of institutions into the community, into their own apartments.

However, not enough care-hours were provided to enable the most severely disabled persons, such as those paralyzed from the neck down, to live outside of institutions. 1979 saw the construction of Kelly Court, a 3-storey apartment complex in which all the suites are wheelchair accessible and attendant care is shared. While this is a large-scale project which provides care and private accommodation for disabled persons, including those who require 2- or 3-bedroom suites for their family, it does not truly promote integration of disabled people into an able-bodied community.

Now I would like to look at legislation and standards of health to ensure architectural access. In 1980 the British Columbia Building Code improved on previous building codes established by the Vancouver City. It ensured that architectural access was provided to newly constructed or renovated public buildings, but the main contribution for apartment buildings was simply to ensure the main entrance was wheelchair accessible. The British Columbia Building Code was updated in 1984 and unlike prior codes and guidelines, new requirements for wheelchair access were integrated into the main body of the Code under Section 3.7 "Design Standards for Building Construction".

Also, the government provided a handbook with facts and illustrations explaining the requirements - example, the movement mechanics of toilet transfers - to assist most architects not familiar with disabilities how to design more functionally acceptable buildings. This handbook has received instant acclaim, and is in heavy demand here and for use world-wide. This new Code is far better than any previous legislation, although it still exempts multi-family units from most requirements. Preliminary guidelines are currently being revised to include all multi-family housing in the 1990 legislation.

In 1981 Canada Mortgage and Housing Corporation and the Cooperative Housing Foundation of Canada set a policy standard requiring every Cooperative financed under Section 56.1 of the National Building Act, to build 5% of its suites for wheelchair living. Most resource groups developing cooperative housing at this time did not have the technical expertise to supervise and design or coordinate the provision of services required. As a result, they were dismal failures.

For this reason, in 1982 eight community-based organizations including the Canadian National Institute for the Blind, the BC Coalition of the Disabled, the BC Association for the Mentally Handicapped, CPA, and four others, joined forces to form a new non-profit housing group called "BUilding Independent

Living with the Disabled (BUILD) to develop integrated 'special needs' housing. By 1983 the first two developments were completed - a housing cooperative in East Vancouver, a stacked townhouse complex; and a housing cooperative in West End Vancouver.

As of 1986, BUILD had completed 14 accessible housing cooperatives, providing 573 housing units of which 11% were modified for use by persons using a wheelchair for mobility. A significant number of unmodified units are occupied by other disability groups not requiring physical adaptations to their environment. In addition, there are at least four other non-profit British Columbia cooperative housing development agencies in following BUILD's example. From the first multi-family projects which allowed self-ownership and management, as buildings were designed with all needs of the mobility-impaired person in mind, there was wheelchair access to all suites in the buildings, that is, all suites and facilities could be visited by an individual in a wheelchair.

British Columbia does have a rental subsidy program designed to make market housing affordable for disabled persons. Under this program, disabled persons pay 30% of their income towards their market value rent and the provincial government makes up the shortfall. This program is generally available only in areas where there is inadequate social housing available. Where low populations or high vacancy rates do not warrant construction of social housing it would be impractical to build a 21-unit building. We then look at having British Columbia Disability Management provide rental subsidy.

Our next aim was to expand housing options to some of the most severely disabled, the ventilator-dependent quadriplegics. These are persons in whom all four limbs are involved. They are paralyzed from the neck down and depend on a ventilator for breathing. September 1985 saw the opening of Creekview 202, an integrated self managed independent living project developed by CPA and at least 6 former residents of Pearson Hospital, five of whom were ventilator-dependent. The apartment occupies the equivalent of 6 one bedroom apartments, 4,700 square feet, in a 100 unit co-operative building which was funded by CMHC and occupied by people with a mix of incomes.

Again, each cooperative member pays 27% of their income for rent and no additional charge is made for support staff accommodation. The apartment has wall to wall windows which look north to the mountains and a wrap around balcony which has private access from every bedroom. There is a spacious

living room, a den or guest room which can be partitioned off by a folding wall. The kitchen provides large enough space for the tenants to participate in meal preparation. There is a computer room where tenants can study, work and manage household affairs. Each tenant has their own bed/sitting room. The specially designed bathroom is placed at the back of the apartment where guests would seldom go.

The Ministry of Health and the Workers Compensation Board have provided funding to the tenants through CPA for purchase of support services such as a paramedic, home-maker, nursing, physiotherapy and occupational therapy. The attendant as primary care giver has been involved in a comprehensive training program by Pearson staff. All six men are equal members of the co-op and one is actually president of the whole building and involved of hiring and firing all staff.

In 1987 an independent evaluation of Creekview 202 was published which confirmed the success of the project in three respects. The cost of providing tenant care was approximately 60% of maintaining the men at Pearson Hospital. Data indicated that on the average the per diem cost to government was approximately \$100 a day less than at Pearson, or a combined cost savings to government of about \$215,000 per year.

The secondary evaluation was with regard to health status. Despite some individual variation, the overall status of the residents appeared to be at least as good as at Pearson Hospital. Physical health was maintained and mental health and social interactions were improved. Government was not interested in measuring quality of life, but if you talk to any of the men they would give you a strong indication of how much it means to have control over their life and be actively involved in the community.

The third area evaluated was standard of care. The Canadian Council of Hospital Accreditation's standards were met and exceeded in virtually all cases.

Our current project is to take the Creekview 202 concept one step further. Presently in the developmental stage is the Nobel House Cooperative which will accommodate 7 severely disabled, ventilator-dependent Pearson residents. This project will provide a self-contained apartment providing room for visiting family and friends and the potential of marriage and as normal a life as possible. All 22 of the apartments in the building are adaptable which means that with minimal changes able-bodied or disabled persons can live in any one of them.

Adaptability means that in every bathroom we are providing for a wheelchair turning radius (this is actually an 'able bodied' apartment) so that if a senior citizen, or someone with a progressive disability like MS ultimately needed a wheelchair all we have to do is put in a grab bar. The tub can be taken out and underneath it is ready to become a wheel-in shower. The sinks are adjustable on a hinge. If you lived there as an able-bodied person you wouldn't notice it but we could send in a carpenter and in 15 minutes adjust it for a wheelchair. The kitchen is the same; we provide a turning radius for a wheelchair and the counter and sink are easily adjusted by a carpenter. And of course we make sure the bedrooms are large enough for a wheelchair to get around the bed. Every room has a call system to call staff because these people are on ventilators.

What we are promoting is that if all buildings are 100% adaptable, instead of putting senior citizens and severely disabled persons in institutions, we design housing needs around one, two or three bedroom units grouped in the same building for cost effective care delivery. They can have their own private apartment but they share staff.

Another recent development has been the establishment of a wheelchair housing registry under the auspices of the British Columbia Housing Management Commission to centralize information previously available in a less coordinated fashion. It is being done to link all subsidized housing and private market housing suitable for wheelchair living with prospective disabled tenants. For severely disabled persons, registration information includes a summary of the support service needs that will facilitate the pooling of hours of attendant care between prospective tenants.

CPA is just finalizing negotiations with the British Columbia Ministry of Health to hire a coordinator of housing and support services who will act in a brokerage role. The CPA broker will group individuals registered at British Columbia Housing Management who require attendant care and then link the groups of individuals to agencies that provide support services and to developers who can provide housing in any variety of settings such as cooperatives, low income complexes or private market developments.

To review the current state of housing in British Columbia, there is the Lion's Paraplegic Lodge, the halfway house. We have legislative standards requiring front door access to all newly constructed housing complexes but a total

building access is yet to come. At least 5% of all new provincially and federally subsidized housing is wheelchair accessible. Group homes for both physically and mentally disabled are available but have not been for the most severely disabled.

We have apartment complexes, some segregated, others integrated in which homemaker and personal care support services are shared between tenants under the long term care program. Co-op housing in which disabled people can be owners and self managers in a community that also includes able-bodied people. We have private market housing rental subsidy programs, the Noble Housing Co-op, and the British Columbia Housing Management Commission's centralized registry for wheelchair accessible housing.

The CPA coordinator of housing and support services will work to group severely disabled persons in order to pool support hours and link them to housing. We also have Leasingham Place which is one of the first apartment buildings in British Columbia which would be 100% adaptable.

I now want to use this opportunity to talk about some of the recommendations that we have for the future and when I talk about the disabled I am talking about seniors as well. Of course the recommendations are based upon the four founding pillars of special needs housing. That is, architectural access, support services, coordination and affordability.

Number one, we feel we should look to the day where we will have legislation which insures that all multiple family housing projects provide wheelchair access to and within, all suites in the building. There is a need for a basic change in the way professionals approach building design. No longer can we afford to construct only 5% dedicated wheelchair suites. We must learn to be more flexible in the creative process. Satia Brink of CMHC spoke in 1984 of "accommodating environments" this theory has come to be known as "adaptable housing". Today we are still constructing senior's apartments in which only 5% of suites are accessible. Frequently this means that residents must move, giving up long term friendships when their mobility declines as a result of the natural aging process. This issue is one of the more crucial because statistics show that the senior population will double in the next ten years.

With regard to changing traditional design approaches, I would propose our universities take a hard look at the core material they use in teaching design. I am told that many universities use the Henry Dreyfuss model and architectural

students were told that if they achieve the design standards for the 95th percentile of the population they would satisfy the market. That misses 5% of the population. We strongly feel that no longer is a three hour course on the 'disabled' portion of the building code enough. All design students must be taught to strive for the 100 percentile from the start.

The second direction I feel we must take is to develop comprehensive community-based health care services that will enable even the most severely disabled person to live in the community. The program must recognize the rights of individuals and their families to be responsible for planning and having active involvement in their choice of care.

Thirdly, there is a need to develop comprehensive programs for rehabilitation and discharge planning from the hospital to the community for spinal cord and other severely disabled persons. Most rehabilitation programs right now are geared to the severely disabled.

Fourthly, under the heading of coordination there is a need to utilize agencies or brokers who have the expertise to assist disabled persons to plan out and access appropriate support care services, housing, etc., necessary to live in the community. The broker may also assist in bringing together groups of disabled persons who could share resources in order to make community living cost-effective.

Fifth, under the coordination banner, there is a need to develop a central housing and shared-support registry, matching persons to accessible units and linking these people with support services as needed. This could be achieved quite readily if we had the centralized housing registry, which could act as a vehicle for determining future housing stock as well as support service needs.

My next obvious recommendation would be that government, at all levels, ensure adequate funding for rental subsidies, private market housing, cooperative housing, and non-profit housing as well as permanent stock.

Finally, we recommend that government provide a 100% tax credit for expenses incurred in renovating private homes to allow wheelchair access.

In conclusion, we feel that 'independent living' projects across Canada, such as the Noble Housing Cooperative, have clearly demonstrated that community living is viable, cost-effective and a desirable mode of housing, even for the

most severely disabled persons. For some people, facility placement remains the housing of choice, but in our opinion institutionalization should be offered only when community living has proved to be more expensive or, for some other legitimate reason, less desirable.

We should work towards the day when accessible, affordable housing and support services are readily available for those with special housing needs - a day when community housing is recognized as a right and expectation of all people in the community.

VIII. AIDS TO DAILY LIVING

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Norah Materi, (Moderator), Kinsmen Rehabilitation Foundation:

The Kinsmen Rehabilitation Foundation is located at 2256 West 12th Avenue, Vancouver, B.C. Hours are 9 to 5, Monday to Friday. Our mandate is "To assist people with physical disabilities to attain independence and equality of opportunity generally available in the community." We achieve this through Rehabilitation Assistance and an Equipment Loan program, the Disabled Living Resource Centre Display, the Library and Information Services, Technical Aids and public education. Through these programs and services, we provide a wide range of assistance to children and adults throughout British Columbia.

The Rehabilitation Assistance and Equipment Loan programs are the Foundation's longest running programs. For over 35 years we have been assisting people with disabilities to make the physical, emotional, and financial adjustments necessary to live active, productive lives. The cost of living with a disability can be over-whelming. The Rehabilitation Assistance program is designed to lessen financial hardship by supplementing basic medical services. It also helps with the uninsured costs of artificial limbs, prostheses, orthotics and orthopedic footwear. Another facet of the Rehabilitation Assistance program is travel assistance, to come from outlying areas to major medical centres, - which can be both traumatic and very expensive - and to help arrange reasonably-priced accommodation.

Our Equipment Loan program provides products like manual wheelchairs, electric wheelchairs and scooters, walking and bathroom aids, portable communication devices, and other basic essential medical equipment. We provide this free-of-charge on a permanent loan basis, and also provide the follow-up maintenance and repair, keeping the equipment in good running order and updating and modifying it as people's needs change. KRF arranges delivery and pickup free of charge province-wide when the client is unable to do this. An Application for Services form must be filled out - and these forms are available from several sources such as your local health unit, hospitals, social services department, PPASS, or directly from the Kinsmen Foundation.

We must make it clear that while the rehabilitation and equipment loan program is wide, Kinsmen Foundation does not duplicate services that can be obtained from other organizations. When we are approached to assist with a problem we will make a referral to the appropriate agency or government program if it is outside our services' scope. After the referral, we follow it up six weeks or two months later to be sure the client has received the required service. If it has not been received, we take further action to achieve it.

Our Disabled Living Resource Centre, established in 1980, represented a major advance in dissemination of information to people with disabilities, their families, rehabilitation professionals, and the general public. The display centre exhibits a wide variety of items available to people with a diversity of disabling conditions. Recently we acquired a new type of kitchen which has height-adjustable cabinets and shelves, and with eating and cooking utensils having built-up handles, non-slip pads for dishes, plates with raised edges. We have a variety of reaching aids, bathroom equipment, bath lifts, shower chairs, grab rails, clothing and bedroom accessories, sewing machine for people with impaired vision, wheelchairs, mobilities aids, new electronic equipment, and many other things in this display. We currently have 1.4 million dollars worth of equipment on loan throughout British Columbia.

We are still operated by volunteers and are not supported by the Provincial Government. We have close relationship with PPASS, the Post Polio Awareness and Support Society of British Columbia - in fact, we share two board members.

We have the Kinsmen Rehabilitation Information System (KRIS) database. KRIS contains information on services, publications, and equipment, and being computerized it is easily accessible to people in remote locations and health professionals throughout British Columbia, Canada, and the world. We have audio-visual material available for loan. Our Centre is used as a setting for instruction by hospitals, universities, professional groups, and the general public. We are probably the best source of information on aids, services, and publications dealing with independent living in Canada. We are the first such resource centre in Canada and the second in North America. All our information is free to consumers.

We believe we are unique in making a promise to you, that if we don't know the answer to your question we will find out. If there is an answer, we will find it for you. We do our researching by phone, letter or other means.

Kinsmen originally started in 1952, with the first Kinsmen Mother's March in response to the Polio epidemic. "Kinsmen" and "Kinettes" are service organizations throughout British Columbia. These volunteers raised funds to buy iron lungs, rocking beds for many polio clinics in British Columbia. When Salk vaccine became available in mid-1950's, we helped purchase the polio vaccine. Since then we have outgrown the ability of doing all the work by volunteers and we reached the stage when it began to be run by 30 persons, 14 of us in the programme department. The great influx of people coming from Hong Kong and other Asian countries included quite a number of children recently affected by polio, and some of them are at Sunnyhill hospital right now.

Our services have expanded beyond people with polio, and deal with people who have any type of physical disability. We provide up to 7,000 services a year. We have a quarterly publication, the "Image", which is free of charge and which has a circulation of 19,000. It is the Foundation's journal and covers many items of interest to people with all sorts of disabilities. If you wish to receive a copy regularly, give us your name and address to be put on the mailing list.

The Technical Aids Program of the Kinsmen Rehabilitation Foundation has been in existence for over 15 years in British Columbia. Its main objective is to provide technical assistance to people with severe disabilities who have extreme physical limitations. Some of the disabilities dealt with by that program include cerebral palsy, spinal cord injuries, rheumatoid arthritis, traumatic head injury, and post polio.

The Technical Aid main working area is the workshop in our building. All of our shop and repair equipment is set up before installation, and all development and manufacturing takes place there. Because service delivery is a prime component of our business, much of the work is done by traveling to clients' homes and hospital settings throughout the province. We have been equipped with a technical aids vehicle by the Kinsmen Clubs of British Columbia and this is stocked with tools, equipment, parts, materials, and other supplies. We travel to all areas of the province as the demand requires - the Lower Mainland, Fraser Valley, the Island and North Coast and the Interior and Northern Interior to a lesser degree.

Environmental control for some with a severe disability is extremely important. It means having control of standard appliances that many of us take for granted - things like lights, TV's, even door opening. To use an Environmental Control device, standard appliances need to be controlled through a central control. This device links all of the operable devices together through an input switch which the person with the disability can actually access - and we call all this an "Environmental Control System."

The first application of an environmental control system by the Kinsmen Foundation was made in 1973 - and, in fact, it was KRF who actually introduced technical aids of this nature to Canada. For the first time in years, Joe Kelly was able to turn her lights on and off, operate her television, and call her friends on the telephone by herself. This system was called the "Possum", a name derived from the Latin verb "to be able". From the "Possum" came a new system called "TALK" and this was used for many years. In 1986 the Kinsmen Foundation developed their own unit. The talk unit itself weighed 40 pounds. You couldn't go far with it and it cost about \$2,500 per unit. The unit developed by the Kinsmen Foundation is the size of a TV Converter, a very little thing and quite lightweight.

The "Kin Control" can control ten different functions such as: an intercom operated to determine who may be calling at the door; a remote doorlock, operated to provide security; a television turned on or off and channels selected; telephone dialing - a very important function for a disabled person - and up to 60 different telephone numbers selected and dialed. As well, with the use of Kin Control, any type of remote control such as a VCR can be operated. The most important factor of the Kin Control is the interface between the user and the Control unit. In some cases a breath-operated switch is used, and there are other input switches which can be operated by just touching the switch with the side of the nose or touch of the tongue.

Non-portable communication systems are provided to severely disabled individuals to answer one of the most important and basic needs - to let others know our feelings and ideas. Portable communication aids are provided through the Equipment Loan Program. One of these was a switch-operated electro-mechanical typewriter system - a limited system because with the touch of a switch you would scan the lights across the top screen. When you reached the letter desired, you tapped the switch again, sending a signal to the typewriter which then printed that letter on the page. To 'say' "hello" would take 4 minutes.

Since then we have come a very long way. With the advent of microprocessors, everyone now can use computers and KRF uses them as part of communication systems for the clients. Programs stored in computer memory allow a severely disabled person to select an alpha-numeric letter, phrases, paragraphs, and pages, and be able to formulate letters, stories, memos, and other printed matter - meaning communicate in what is the normal method of corresponding with others. This is achieved by using only one small switch.

Other systems such as the speech pack can be accessed via keyboard - and the speech quality in this pack is excellent - with one pack having a male voice, another a child's voice, another one a woman's voice. There is the "Light Talker" which utilizes a small light mounted on a pad and which interacts with the keyboard, but this system uses a different type of language. It is called "Minspeak" meaning that children don't have to learn letters and call things up an alphanumeric character at a time. Instead, the child uses it by identifying pictures of objects and things.

"Kids on the Block" is an educational puppet program designed for elementary school children, with a cast of disabled and non-disabled puppets. The program helps foster positive attitudes towards people with disabilities, promoting awareness of the services of the Kinsmen Rehabilitation Foundation. The Foundation is providing all the environmental control call-bell systems to the Noble House Project. Three of the first occupants of apartments will be polio survivors who are respirator-dependent, each of whom will have their own control unit. Doors will be operable by such a unit attached to their power chairs.

The Kinsmen Foundation Technical Aid Department basically can come up with any switch-design to access any movements that a person might have - even the slightest movement. There is the magic velcro pencil-holder - a nifty little device like this which is just a piece of plastic with two pieces of velcro on it. You can put a pencil, or tool or utensil in it and you don't have to grip the article to make it work. The temperature control faucets are for people who can't quite feel the temperature change of their water, or if they can't turn a tap, they can be set for a specific temperature for a bath.

Wheelchairs should have solid seats. They should be built like you build a house - with a solid foundation. We often see sling-seat upholstery on a wheelchair which "hammocks" over time, that is it develops a big curve and the

body starts going inward towards the centre of the chair and creates bad posture. If this upholstery is replaced by a "solid seat" insert, not only does it eliminate "hammocking" but we can put a "J-cushion" on it. This "J-cushion" is a three-piece unit. One piece is the cover - which is an air-exchange fabric over a 97% air foam inside it.

This means that every time you do a weight-shift and move your body, you get a fresh layer of air in between your body and the cushion - and it stays cooler. It is a flow-like pad which is not a gel but a fluid and this is for pressure-relief. The third piece is the base. This is dished out at the back, slightly pummeled in the centre at the front for leg separation. As soon as a "J-cushion" is placed on it, you can see that the person sitting on it is sitting up straight, hips to the back of the chair. With the flow layer on top of it we have pressure release. So first posture, then pressure release, then the air exchange cover. This unit is attached by velcro so it is easy to put on or take off.

There is a new back for the wheelchair. The old upholstery is removed from the back section and is replaced with the same type of unit as we have put on the seat. This is done in different sections so that gravity will not pull it down to the bottom - and this protects the spine. There is lots of velcro with lumbar support and it also comes with good lateral supports. We remove the "sling" upholstery and replace it with a custom seating system for each individual person - it fits them like a glove, is always comfortable, and it relieves the pressures.

There are a few things about equipment selection which the disabled person should consider. There is an incredible variety of equipment available today and this is because there are so many different kinds of disabilities. As polio survivors, I think you will agree there are no two of you who has the same type or degree of disability or need. What many manufacturers try to accomplish, is to work with modular systems that can be adjusted to the needs of your disability in the least expensive way possible. The "J-cushion" is now a classic example of modular systems. The manufacturers must create a huge product range for this variety of disabilities.

When you try to buy something, it is usually in your best interests to get good advice - from specialists such as an occupational- or physical-therapist. It is necessary for you to know what you plan to do with the piece of equipment, what your disability level is, whether it will remain at the same level, what is considered best for your own situation, what the cost level would be, the source

of the necessary funding, and so on. For instance, if you are expecting your physical condition will degenerate over a short period of time and you need the right kind of chair for yourself, your decision may be to go right to the motorized wheelchair and not the intermediate step of buying a scooter. A wheelchair is the base from which you will build your long term seating arrangements, your customized seating system, your customized environmental control system, and so on.

Nowadays you can adjust almost anything on power wheelchairs. You turn it on and there are fully proportional joy sticks; variable speeds from low to high and reverse; turn response; acceleration and deceleration; and controls suitable for almost every type of disabled person. Also, using very strong and very lightweight materials, the lightweight chair is now manufactured in large quantities, and combined with other hi-tech discoveries and systems to address your real needs.

The motorized scooter is becoming more and more popular and it is a rapidly growing market. The reason for this is that scooters look like little cars, something very nice, and people use them to take them the 10 blocks to the grocery store, to go around the mall. Many people are semi-mobile and by use of cane or crutches they can do many household tasks and activities, but for moving any distances they must rely on some form of vehicle. And scooters are now quite portable - they can be easily disassembled into parts that can be stowed in the car trunk. There is also the "scooter tote", an apparatus you put on your car and this unit will carry a scooter on your car in the same way as people who have bicycle racks transport their bicycles.

The Kinsmen Rehabilitation Foundation is committed to public education functions, to be active in special display projects, consultations, teaching sessions and practicum sessions, and workshops for the public. It collects articles and other information on Post Polio. We have many connections with people who have had polio - this is an important part of our historical development. This information is sent out to anybody who phones and asks for information on post polio. We provide them with the information and we try to link them up with the Area Group of PPASS nearest to them.

The Foundation is involved in putting together a Workshop and a Directory of Consumer Health Information Resources, and these are being presented at the "2001 Conference" next month - which is sponsored by the British Columbia Health Association. This conference is drawing a tremendous number of health

professionals from all over the world. The Foundation Librarian is a member of the Conference Panel of Librarians and has been collecting information about all agencies and health organizations we've found, including PPASS.

AIDS TO DAILY LIVING: Questions and Answers

Question: About the Jay cushion. If you get a hole in it does the air leak out? If it does, what can you do about it?

Answer: It can leak just a little bit but very, very slowly. It can be patched. Another thing about the Jay cushion is that you knead it once a week to keep it consistent, to keep the material mixed up.

Question: Do they make the Jay inserts for all sizes of wheelchairs?

Answer: They start at 14" width and go up to 22" but they are really custom-fitted for the person's own needs.

Question: Can you wash them?

Answer: Yes, with warm, soapy water, then wipe it with a cloth.

Question: When the Jay cushion is all together what does it weigh?

Answer: The regular adult size weighs 9 pounds six ounces.

Question: What is the best way or how should we choose a wheelchair?

Answer: A young, active person who moves about a lot and does out-door activities will be looking for a chair suited for such active movement. If you believe your condition will be degenerating over a period of say five years, then

you must think of what you'll need at that time. You are buying a chair with 10 to 20 years usage in mind. The Kinsmen Rehabilitation Foundation has a very good written article about this called "Choosing Your Wheelchair. How to Pick for Yourself."

Question: What about just buying a cushion - to sit on chairs, etc.?

Answer: The "Flo-Lite" pad is a very fine unit. It is expensive. If you have it on your van seat you can't really take it with you. There probably will be some portable ones on the market sometime, perhaps in the near future.

Question: If my wife just wanted to get only the cushion?

Answer: It is \$450.

Question: Is it covered under my Medical Plan?

Answer: With a prescription it is.

Question: Does that come with the back as well?

Answer: No. The back unit is \$620. Cushions now are like chairs - there are thousands of different types of cushions available ranging from fairly good ones at \$180 and going up from there. The type you'll need you have to decide for yourself but you can get help in deciding what is best for your personal needs. Are you going to be sitting in one position for a long time? Do you need something allowing you to change weight from side to side? Again, KRF can give you a lot of help that way. They can do some searching for you and get you a list of guidelines to follow and give you a good idea of the range of suitable cushions available for you.

Question: I'd like to know more about the "Kids on the Block" show.

Answer: "Kids on the Block" is an educational puppet show that has nearly life-size puppets. They are so well made they are "children." There are

"children" without any disability but most are "children" with a variety of disabilities. One puppet is visually-impaired; another has spina bifida, one has cerebral palsy, another is mentally handicapped, one is learning disabled, and one puppet has epilepsy.

For grades 3 - 7 school children we have two puppets who visit schools and put on a 45 minute performance, usually the audience is approximately 250 school children. The puppets produce skits, and usually there is an able-bodied puppet interacting with the puppet with the disability. They introduce each other and, for example, 'Spina Bifida' says "Oh my God, what's that on your leg?" since she's referring to braces. As the skit goes on the puppets ask the school children if they have any questions. This gives children an opportunity to interact with a puppet instead of with the adult who is, all in black, behind the stage manipulating the puppets.

Question: Do you have any pictures, literature or handouts on "Kids on the Block"? The reason I ask is that my daughter has a child with cerebral palsy and my other grandchild is hearing impaired. This kind of thing would be interesting in the work my daughter does. I'm from Seattle and I haven't heard of anything like it down my way.

Answer: "Kids on the Block" is copyrighted by a group in Washington D.C. but located now in Maryland. It was created by a group of special education teachers. We believe there is a troupe of the puppets in the Seattle area, although not Kinsmen. If you'll leave your name, address and phone number we'll do some checking for you. We have a list of the organizations that are doing the puppets and we'll send you the list or the name of the group in Seattle or the group closest to you. It isn't hard to get a group going. The set of puppets costs \$42,800 U.S. and comes with all the scripts and how to train a puppeteer.

IX. ACCESSING INFORMATION

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Jeff McMurchie (Moderator), B.C. Coalition of the Disabled:

Gary Colley, British Columbia Coalition of the Disabled

John Madison, Pacific Transit Cooperative & COMPACT

Trish Salisbury, Surrey Parks & Recreation

Carolyn Porter, North Shore Handidart System

Nine months ago a task force was appointed to investigate transportation and recreation for the disabled of British Columbia. Hearings were held in nine regional centers. The task force invited consumers, local politicians, service organizations, and other community groups to present briefs about problems of the disabled with reference to transportation and recreational facilities and services. It has published an overview of it in "Transition". This workshop will focus on transportation and recreational services and facilities available in Vancouver and British Columbia.

Since the Charter of Rights and Freedoms came into effect and the "Year of the Disabled" was universally celebrated, many disabled persons and groups of disabled people have been able to speak out about issues which concern them.

Of particular interest here, is ease of access to transportation to and from locations anywhere in Canada. As a result, discounts are now available to allow essential attendants to travel with the physically disabled on motor coach lines, VIA RAIL and many local transit systems. Airlines now have a training program teaching airline attendants to deal with the needs of a disabled person, and the latter's companion travels at half fare cost. It is advisable to contact the airline well in advance of the time you are planning to travel. Request to speak to the airline person who deals with disabled persons. They will make the necessary arrangements for you and have attendants on hand to help you at both your local and destination airports.

The British Columbia Ferry Corporation has special ID Cards (i.e. personal identity cards) which allow a disabled person and attendant/companion to travel for passenger half-fare. It doesn't cover the vehicle, however, for which full vehicle fare is charged. This ID card can be obtained from PPASS, British

Columbia Ferries Corporation, Canadian Paraplegic Association, Kinsmen Rehabilitation Foundation, or community groups like SPARC.

In some major centres like Vancouver and Victoria, there are additional transportation assistance such as the Parking Meter Exemption sticker, obtainable free of charge from the City Hall. The disabled person's doctor must indicate the disability and sign the application form. A Bus Pass for people on GAIN "Handicap" is available at a cost of \$36 per year, but these do not work on Handidart or other custom transit services. This is something we are working on. We have also obtained the right to this Bus Pass for people not as severely handicapped or on GAIN.

In Vancouver the Canadian Paraplegic Association rents a van for \$20 per day. This van can only be used within the boundaries of British Columbia. There are limited numbers of these rental vans. Contact CPA by telephone well ahead of the time you will need the van. The Worker's Compensation Board has a lift-equipped van available to disabled people but on a day-only basis because they have their own, sometimes pressing needs. Hertz and Avis car rental agencies have hand-control cars.

A Gas Tax Rebate is available for a Disabled Driver. In British Columbia the rebate is the full tax that is charged on each litre of gas. Federally, it is the 1.15%. Therefore, you get back about 1 cent plus a little more per litre.

HANDIDART is a "parallel public transit system" for people with disabilities who are unable to use the conventional system of British Columbia Transit. Handidart is a 'shared ride' system funded by British Columbia Transit and by the British Columbia Regional Transit Commission. Any seriously disabled person who is eligible and wants to use Handidart, should call the local Handidart operator to register. When you register, you are required to give name, address, phone number, and your doctor's name and phone number. You will be asked for the type of mobility aids you use, such as wheelchair, electric wheelchair. There are regulations governing electric scooter transportation, and you will have to sign a disclaimer waiver before you can ride seated on your scooter in the Handidart van. These vans are equipped with power-lift devices for wheelchairs. To book a trip, call the Handidart operator, make a reservation giving name and rider number, and book seven days in advance. You must give your destination, time there, time for pickup.

COMPACT is a group of consumers promoting accessible, conventional transit on the Seattle transit model and trying to get this model applied to the Greater Vancouver area. In March, 1990, British Columbia Transit will have wheelchair-lift buses in the Vancouver system representing 10% of its fleet of buses. Within 5 years it is expected that the fleet of buses and the routes will approach 50% on a wheelchair-accessible basis. The advantage of an accessible conventional transit system is that disabled people will be able to go to a bus stop and get on a bus with all bus passengers, and won't have to book a trip a week in advance for a trip on the Handi-Dart. Some problems will have to be ironed out. It is doubtful if wheelchair accessibility will ever be provided on trolley-buses.

Handidart funding will be fairly static for the next 3 years until wheelchair accessible service is in place. "Wheelchair accessible" is a somewhat restrictive term - it means a wheelchair person has the wheelchair lift on the bus - but the meaning has been extended to include the lift-assistance for Seniors and disabled persons with walking disabilities that require lift-assistance to get around. Initially, the buses will have two spaces on each bus. Also, in Seattle they have articulated buses - buses that have two (or more) cars joined together, and they bend in the middle. COMPACT is also working with British Columbia Transit to try to achieve the Seattle level of accommodating those who must go about in wheelchairs or who have ambulatory trouble.

RECREATION and LEISURE benefits don't allow disabled people the same freedom of activity that the general public enjoy. Basically, recreation gives people a chance to relieve boredom, learn new skills, meet other people, enter into many community activities. Our commission supports recreational programs of a broad nature, so it is easy for persons to participate in a program they consider most suitable for their own desires or needs.

We have a staff person in our special need section who goes to people's homes to discuss with them recreational topics to assist them in deciding a program they would enjoy doing. They also determine what their physical abilities are for participation or even transportation to and from the recreational facility. We have a pool and wheelchair people enjoy it, and we have assistants who can help them. We have many disabled persons' and seniors' programs which often appeal to those who have more serious physical disabilities because of the nature of the programs. People like to get out with other people, to share recreational and fun activities, to challenge their minds with things like chess, bridge, other games, as well as many different kinds of hobbycraft.

Make use of the many types of leisure and recreational activities and the environment of your own community. The change of pace can be very exhilarating and very worthwhile. Try it! Recreation departments are listed in the telephone blue pages. You can also check with the local Chamber of Commerce or with the Municipal Offices. They can tell you where the local community centre is located. Often, smaller communities have better identified recreation departments than the large centres. Sometimes the nearest recreation facility is in a school or in a church hall, etc. You may be someone who is shy or defensive with new people. We are usually able to help each person to be at ease, to enjoy it all.

ACCESSING INFORMATION WORKSHOP: Questions and Answers

Question: The Gas Tax Rebate only applies to persons who drive their own vehicles. There are disabled people who have to travel in a vehicle driven by someone else and the rebate doesn't apply to them. This is a ludicrous situation because they have the same need to travel - it could even be their own vehicle - so is there anything being done to correct it?

Answer: We are lobbying the government for 2 specific exemptions. One is for the disabled vehicle owner requiring someone to chauffeur him in his own vehicle. We believe he has just as much right as to the more fortunate disabled person who is able to drive himself around. At present the regulations that cover the gas tax rebate require that the disabled person not only must own the vehicle, but have a valid driver's license. The second exemption we are lobbying the government for is to amend it for groups, specifically group homes, that have a vehicle available to the residents for their traveling needs to go anywhere with a designated driver. We feel they should be eligible for the tax rebate, too.

Question: Do you report a gas tax rebate as income for income tax?

Answer: No. The tax rebate coming back to you is not income. It is just an expense refund to you. Currently, the new rate for rebate is 10.88 cents per

litre for leaded gas and 9.88 cents per litre for unleaded. When you apply for the provincial gas tax rebate, you can either access every three months, six months, or yearly. Obtain the Gas Tax Rebate form and apply. This exemption makes you eligible for an ICBC discount on your auto insurance which ranges from 35% up based on your "Good Driver Discount" rating. If you have the full Good Driver Discount, the Disabled discount is in addition.

Question: I have had problems at the airport - I don't know if it is bad communication between travel agency and airline or not.

Answer: Call the Airline main office direct, and outline your needs and have them make the arrangements for you at the airport. For any problem, at either end of your trip, get in touch with the airline's main office and outline your problem. Even write them a letter. They usually take prompt action. If it is an ongoing problem and no satisfaction is in sight, take it up with a good consumer advocacy group to handle for you. The airlines are there to serve the public and they have training programs to teach their attendants how to handle disabled persons, how to load and unload them, to take the necessary special care. Airlines themselves want to know if their services are not being properly provided so they can correct the situation and improve it.

Question: Isn't that a small number of spaces for wheelchair people on a bus? Do articulated buses take more wheelchairs?

Answer: A two-car articulated bus is much longer than the ordinary bus and this longer bus will handle 3 or maybe 4 wheelchairs at one time. If the bus contains its limit of wheelchair passengers, then it can't stop for another one, and so that wheelchair person has to wait till the next bus comes. In the future it may be that buses will allow more wheelchair space but probably this will never be during the rush-hours.

Question: How do you find the recreation department in your own community, especially if you are new to the area?

Answer: Most recreation departments are listed in telephone blue pages, but check with the local Chamber of Commerce office or the Municipal Offices. They can tell you where the local community centre is located.

Question: Will the Handi-Dart system be decreased because of the new buses and conventionalizing wheelchair and disabled travel?

Answer: No, that isn't expected because the need for a parallel transit system probably will always be there. But it will greatly improve the freedom of movement of disabled persons and eliminate many of the difficulties involved in pre-booking the Handi-Dart so long in advance. Obviously, if you can go out to a bus stop at any time and be able to get on the conventional transit, most of us will do it. But for going to meetings and recreational programs and things like that, it may be a regular thing and it'll still work well for you to keep a regular service in place for your convenience and assistance. Conventional transit may not be the way to go in those circumstances. But, you will have a much greater choice in the future.