INFORMATION SYSTEMS AND ELECTRONIC AIDS FOR THE PHYSICALLY DISABLED

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Kinsmen Rehabilitation Foundation of British Columbia

Introduction

The Kinsmen Foundation of British Columbia, since it's beginning in 1952, has supplied services to physically disabled individuals and groups in British Columbia (B.C.). The following material describes the three major service programs of the Foundation emphasizing access to information and electronic aids and systems for the disabled.

Over the past thirty-five years the philosophy of the Kinsmen Foundation remains that of contributing to disabled individuals in a way that "they may attain the maximum independence their own will and our help can give them".(1) This philosophy still exists and reflects itself throughout the services and programs of the Foundation. In fact, the mission statement of the Foundation reads: "To assist people with physical disabilities to attain independence and equality of opportunity generally available in the community".

The Foundation is located in the city of Vancouver, but exists as a service centre for all of the province of B.C. British Columbia is Canada's westernmost province with an area of 400,000 square kilometers and a population of approximately 2.9 million. Individuals with physical disabilities use the Foundation as a source of information and direct services. Volunteer support comes from over 70 B.C. young men's clubs called "Kinsmen Clubs". These clubs are dedicated to community service.

The three major program services of the Kinsmen Rehabilitation

Foundation include the Disabled Living Resource Centre, the Rehabilitation Assistance/Equipment Loan Program, and the Technical Aids Program.

The Disabled Living Resource Centre

Prior to the opening of the Disabled Living Resource Centre (D.L.R.C.) in 1980, disabled people searching for answers to problems associated with a physical disability had little access to information. The need for a centralized, comprehensive information service was apparent and the Kinsmen Rehabilitation Foundation was in a position to establish the Disabled Living Resource Centre; the first of its kind in Canada(2).

Equipment Display Centre - the display area incorporates approximately 655 sq. meters, with more than 400 aids and equipment items. Types of aids range from simple mechanical access devices to a higher level of electromechanical assistance devices. Specialized kitchen appliances, adaptive eating and cooking utensils, bedroom and living aids, bathroom equipment, clothing designed for various disabilities, accessibility and mobility aids, and a wide range of communication devices for the speech impaired, are on view in separate sections of the Centre.

Library and Information Sources - the library contains materials and resources focusing on independent living for disabled people. Topics include practical suggestions for clothing adaptation, travel access guides, building codes and home modifications, leisure activities and many more.

Hard copy information includes: pamphlets and brochures, equipment catalogues, books, periodicals and newsletters, films, videotapes and audiovisuals and multi-media kits.

Computerized Information - the Kinsmen Rehabilitation Information System (KRIS) is a computerized information storage and retrieval system developed by the Resource Centre Librarian and computer consultants. It is composed of a KRIS Subject Descriptor Classification Scheme and Index containing approximately 2000 index terms. The databank itself contains approx. 5000 records pertaining to services, publications, suppliers, organizations and equipment.

Information Service - enquiries from disabled individuals, family and health professionals are directed to the resource centre. Information is distributed to individuals through visits to the centre, (both individual and group tours), telephone and written enquiries, information packages, referrals to other organizations, database searches, and publication loans.

Information displays are periodically set up by the centre at shopping malls, conferences and events that focus on services for the physically disabled and/or the general public.

The Rehabilitation Assistance/Equipment Loan Program

The Rehab. Assistance Program is designed to provide assistance to disabled individuals by supplementing existing medical rehabilitation services in the province of B.C. Those individuals, while earning enough to support themselves in a reasonable manner, find the cost of special devices and travel to treatment centres too great a strain on their financial resources. The program gives financial assistance to provide such services.

Equipment Loan - The equipment loan provides items of recoverable standard equipment needed by disabled persons. Equipment such as standard and electric wheelchairs, bathroom

aids, walking aids, patient lifts and special seating systems are available for loan.

Referral Service - Services provided by government or other agencies are not duplicated by the Rehabilitation Assistance Program. Referral to these other services however, is provided on behalf of a disabled client. The agencies or programs are contacted and follow-up is provided.

The Technical Aids Program

In early 1972 the Kinsmen Rehabilitation Foundation of B.C. initiated a new program to research availability of technical systems designed to bring some measure of independence to the severely physically disabled, including those who had lost speech as well as physical functions.

The first installation of a POSSUM(3) Environmental Control System was made in 1973. Over the past 16 years, the T.A. Program has provided services and equipment to more than 2000 clients. The current active client list in 1988 totals 352. 190 clients are presently using environmental controls, 132 are using communication systems and 30 are using a combination of both.

The program assists individuals with physical disabilities resulting from High Level Quadriplegia, Cerebral Palsy, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Muscular Dystrophy, Rheumatoid Arthritis, Post Polio, Head Injuries and others.

Locations for technical aids systems include client homes, nursing homes, group homes, schools, rehabilitation units, and extended care and acute care centres. Requests for technical aids service originate from various areas of the province of B.C. Staff travels to these areas as the demands require.

A typical tour would be travelling from Vancouver to the Interior of B.C. delivering services to 5 to 10 individuals, travelling 1600 km., over a period of 4 days. A technical aids vehicle, complete with a parts and supplies inventory, is also provided for maintenance and installation requirements.

Description of Services

The program has two areas of concentration: **Environmental Control Services** and **Communication Services**. These services both provide:

- 1) **Application and Referral** - individual cases are studied in conference for possible service provision based upon submission of a Client Information Profile. Referral to other agencies or programs is provided if the client does not require Technical Aids Services.

- 2) **Assessment** - performed by Technical Aids staff along with client, family, and involved clinicians.

- 3) **Provision of Systems** - includes familiarization, instruction, setup and installation of equipment.

- 4) **Temporary Loans** - equipment loans provided for assessment purposes. Clients may have to work with various aids until the appropriate system is found.

- 5) **Follow-up** - determining system suitability, understanding, and use with a view towards possible upgrading or exchange.

- 6) **Maintenance and Repair** - providing assistance to clients in the event of equipment malfunction.

Environmental Control Services - primarily deals with providing severely disabled persons with methods of access to standard equipment in their environments. Standard equipment normally

refers to appliances such as intercom and door locks, telephones, television, entertainment systems, bed control, lights, tape recorders and call and alert systems.

In order to efficiently supply environmental control services to our severely physically disabled clients, standardization of equipment hardware becomes a necessity. This not only alleviates a variety of setups but makes replacement easy when equipment failures occur.

Instead of utilizing an Environmental Control System with all functions or peripherals contained in one unit, we prefer to use a component type of system. Our own designed "KINCONTROL"(4) unit acts only as a controller. It provides access to a number of peripheral devices through designated outputs on the rear of the unit. Thus all peripherals (eg. telephone operation) are easily connected or disconnected from the main controller or Kincontrol. This not only affects easier installation or upgrading but allows for rapid exchange if a breakdown occurs. Also each peripheral unit or control function can be individually operated without the use of the Kincontrol provided the appropriate control switch is used.

Communication Services - deals with providing non-vocal physically disabled individuals with augmentative communication systems. These services include:

- 1) provision of portable communicator aids and non-portable communication systems.
- 2) supplying and mounting hardware and control switches for communicator access.
- 3) referral, consultation and public education including

organization of seminars and workshops.

Portable Communication Aids

Portable communication aids (the term portable refers to a communication aid that can be carried and is not necessarily mechanically mounted) are loaned on a permanent basis to clients upon assessment by community and hospital therapists. Most of these communicators can be classified as direct access devices and range from low vocabulary to unlimited text vocabulary devices. Some of the communication aids contain memory locations for storage of commonly used phrases. Output formats can include visual display, and/or printer display and/or synthesized or digitized speech.

Because of the wide range of individual needs, a variety of portable communication aids are available and are selected from our inventory by therapists for clients through an initial and follow-up assessment basis.

Non-Portable Communication Systems

Communication Aids that are not directly accessed (i.e. keyboard operated) and are not easily transported by physically disabled persons are referred to as Non-Portable Communication Systems.

In the early beginnings of the Technical Aids Program, systems relied on scanning systems connected to electro-mechanical typewriters. The arrival of micro-processor technology altered these systems drastically and gave rise to systems with a variety of access methods and possibilities for text processing.

The Technical Aids program utilizes a number of these types of systems including:

- systems utilizing communication software, personal computer

and input ability switches.

- systems utilizing keyboard emulators (eg.adaptive firmware card (5), Tetrascan(6)), personal computer and a variety of software.

- systems utilizing hardware and software dedicated entirely as a communication aid (eg. Scanwriter(6), Lightalker(7))

Funding and Support

Funding is provided for all programs through an annual fundraising campaign called the "Mothers' March" utilizing over 35,000 volunteers. The Foundation itself is entirely self-supporting.

It is important also to mention that Program Services are highly dependent on assistance from professional teams, agencies and volunteers. Therapists, teachers, clinicians and health professionals contribute greatly to assessment and client training. Kinsmen Club members, British Columbia Telephone Pioneers, and volunteer technologists help with equipment installations and repairs. It is through this assistance that the program continues to be successful throughout the province.

References

- (1) Twenty-five years of Caring, K.R.F., 1977, p.4.
- (2) IMAGE - Information Bulletin, vol.15, no.4.
- (3) "Patient Operated Selector Mechanism", Aylesbury, Buckinghamshire, England.
- (4) "KINCONTROL", TASH, Inc. Toronto, Ont., Canada.
- (5) "ADAPTIVE FIRMWARE CARD", Adaptive Peripherals, Inc., Seattle, Wash., USA
- (6) "TETRASCAN & SCANWRITER", Zygo Ind. Inc., Portland, Ore., USA
- (7) "LIGHTALKER", Prentke Romich Co., Wooster, Ohio, USA