Library Services for People with Disabilities in Institutional Settings

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Introduction

Libraries and library services for patients have a long history internationally, with a traditional focus on the therapeutic role of books and reading in the rehabilitation of patients. The International Federation of Library Associations and Institutions (IFLA) provide a set of guidelines for libraries serving patients and people with disabilities in rehabilitation facilities. The main objective of these guidelines is to foster the well being and recovery of patients through hospital libraries offering a range of materials and services; for example, therapy, education and training.

In this paper a holistic model to modern library service development is discussed with particular application to aid rehabilitation towards independent living. The role of the public library in complementing such a program is also discussed.

Library Services for Recovering People in Institutional Settings

In most hospital and rehabilitation settings – medical/hospital libraries are solely for hospital staff providing specialist academic resources intended for staff rather than the patients and their families (Rennie, 2003). The Working Group involved in producing the International Federation of Library Associations (IFLA) Guidelines noted how the term 'hospital library' has different connotations. For instance the term implies a biomedical/health sciences library in some countries, while in others it is defined as a patients' library providing leisure/recreational reading, health information resources or both (IFLA, 2000, p.3).

However, inconsistency in types of library services in institutional settings has been reported to range from sophisticated ‘freestanding’ patients’ library to mobile book services provided by non-library hospital departments to library services facing closure due to lack of funding resources (IFLA, 2000).

According to UN estimates (United Nations Enable, 2014), 15 per cent of the world’s population, or estimated 1 billion people, have a disability.

The challenge for libraries is providing appropriate library services for such a distinct group of people. Within institutional settings comprising services for people with disabilities, the elderly and the chronically sick there are a number of categories.

Hospitals

A hospital is a licensed institution that provides short or long-term care for any number of health related problems or conditions. It is primarily engaged in providing medical, diagnostic and major surgery facilities for medical care and treatment of sick and injured persons on an inpatient basis under supervision of licensed physicians and 24-hour nursing
service. A hospital does not include a convalescent home, rest home, nursing facility or a facility affording custodial or educational care, although some hospitals have specialty facilities such as rehabilitation or nursing care centres. Some hospitals may have a hospital/medical library solely provided for health professionals or for a specific patient user group – for example, libraries on cancer, or libraries for expectant mothers.

Nursing/Rest Homes
A nursing home may be a public or private establishment to provide living quarters and care for the elderly or the chronically ill. In most countries, these are licensed and/or run by the state. They may provide a variety of services including a room, meals, recreational activities, assistance with activities of daily living and protection/supervision to residents. Some nursing homes specialize in areas such as Alzheimer’s disease, pain management, incontinence training and cardiac rehab. It is becoming more common for public libraries to provide recreational/leisure collections to clients in nursing and rest homes; this is certainly the case in New Zealand.

Rehabilitation in New Zealand - Spinal Cord Injury
In New Zealand it is estimated that there is one new case of spinal cord injury (SCI) every five days. Motor vehicle accidents account for most cases of SCI until the age of 45, with falls accounting for most injuries in the age group 45-60 years.

Methodology
The New Zealand Spinal Trust (NZST) is a charitable organisation which was founded in 1994 (by the late Professor Alan Clarke) to address the unmet needs of rehabilitation, information, research, advocacy and support for people with spinal cord injuries throughout New Zealand. The NZST administers a range of services one of which is the Allan Bean Centre (ABC) Library situated on the Burwood Hospital campus in Christchurch.

In an unpublished paper (Clarke, 2000) presented at the First National Conference of the Spinal Network “Life beyond Bugger!” Clarke stressed that successful rehabilitation is hard work, involves personal learning, and is the responsibility of the recovering person. As the major stakeholder in outcome, the recovering person is the ‘chairman of directors’. Everybody else is ‘staff’. Rehabilitation professionals, programmes and centres need to recognise this and provide the resources and support to allow it to happen.

For patients to be in the driving seat of their rehabilitation they must have access to quality information. This access must continue during and after their stay in a rehabilitation centre, making a library essential.

Allan Bean Centre
Burwood Hospital is New Zealand's largest and most comprehensive rehabilitation campus catering for spinal cord injuries, brain injuries, stroke, orthopaedic conditions, cardio-respiratory, pain management and related concerns. Every year, more than 2,500 people recover from injury or illness at Burwood Hospital. The Allan Bean Centre (ABC), situated on the Burwood Hospital campus, is a unique centre providing a range of services and resources for people recovering from serious injury and illness. Rehabilitation starts from day
one. For example, as soon as patients arrive in the Spinal Unit and their injuries stabilised, they commence a rigorous programme of physiotherapy and occupational therapy treatment as necessary.

There is no doubt that spinal cord injury is a massive sudden change in the life of a victim. The model adopted by the ABC acknowledges the possible traumatic effects of a sudden change in life over and above the trauma of the physical injury, in order to minimize the adverse outcomes. Specifically:

- **Hope**: An information pack is issued to all patients and their informal support network (e.g. family members). The information pack emphasises and prepares the patients, with examples, that a “normal” life is achievable.
- **Informed decision making**: Provide relevant information for both the patients and their support network, and indicators on how to find out more about their condition, list of services, others like them etc and how to formulate what they would like to do – there may be a need for retraining, or restructuring
- **Support services**: once patients have made a decision they invariably require support to achieve their goals. These services may be in the form of simply providing access to the Internet, (re-) training programmes, or putting them in touch with relevant formal support services (e.g. social services) or local community organizations, including the local public library.

The development of the Allan Bean Centre Library

The model adopted to develop the ABC library and information service is holistic and evidence-based. The recovering person needs access to a range of resources whether it is information about their injury/illness, pain management, retraining, learning new skills and/or returning to work or gaining new employment. Therefore, the ABC library and information service is not a traditional medical library. Rather, it is available to everyone i.e. patients, families (whanau and caregivers) as well as hospital staff, students and researchers.

The main distinguishing feature of the ABC model is that it is evidence based. This means initiatives are developed on the basis of the ongoing identification of the information needs of clients. One of the advantages of this model is the move away from resource-based learning towards a client centred learning. The model adopted by the librarian follows a dynamic approach of assessing the needs of its clients by continually consulting all stakeholders (Cassidy, et al. 2004).

It is important to remember that the aim of rehabilitation at Burwood is not just physical healing. The philosophical aim of placing the patient in the driving seat for their recovery provides patients with a pathway to return to an independent life which may include having a job, performing daily activities and so on. In this context, the stakeholders may be the patient, their informal support network (family), formal support network (health practitioners), and the library staff. Each stakeholder will need the library to support them in meeting their different needs.

From the Librarian’s point of view the library and its services must be appropriate and relevant for its clients. From the practitioners’ point of view they require access to up-to-date information and literature. From the patients’ point of view they require the understanding that they have suffered a massive traumatic change in their lives. Over and above providing information on the patients’ injury/illness the library needs to demonstrate proof that, there is indeed, life after serious injury or illness. For example, the library includes numerous
histories of previous patients who through retraining have returned to full time employment and a “normal” life. A unique feature of the ABC library and information service is to acknowledge that although it is the patients who sustained physical injuries, their injuries have impacted on not just their own lives but also the lives of all around them, e.g. family/whanau.

**Results**

**The ABC Library Facility**

The ABC Library is a purpose built single storey building specifically designed for people with disabilities, the building is situated next door to the Burwood Spinal Unit and won a national award for its breathtaking design. Inside the Library is spacious, with adjustable height tables, custom designed shelving allowing people in wheelchairs to be able to browse the bookshelves independently, and includes pull out shelves. The ABC has been innovative in developing voice-activated bed-side computer stations called ‘EmpowerPaks’ in the Spinal Unit for tetraplegics. Patients who are on bed rest often visit the Library to use the facilities accompanied by nursing staff or family members.

The Library has between 6000 - 8000 users/visitors per year and provides over 300 free computer training classes annually. An Internet service is essential for patients of the Burwood Spinal Unit, Brain Injury Unit to maintain contact with their families via e-mail, Skype and social media which are not available on the Burwood Spinal Unit wireless system. The computers are also used by patients and families to work remotely while either they or their whanau/families are staying in the Burwood Spinal Unit. Hospital computers are available for hospital staff to access work related information, databases, and e-journals.

All the Library computers have free access to the Internet and email with photocopying, printing and scanning facilities available. Information relating to an individual’s injury or illness is provided free - other additional information can be printed requiring a donation towards printing costs. Equipment for viewing videos is also available in the ABC Library. There is a range of assistive technology for people with disabilities to be able to access the computers, for example, track balls, voice recognition software. Meetings and group sessions are often held in the library, but the layout also allows the opportunity for quiet study. The atrium adjoining the library is used as a social area for seminars, meetings and lunches etc.

The Allan Bean Centre Library is a quiet and peaceful place where patients can escape the confines of the hospital setting in a safe and supported environment, where they can explore information about their rehabilitation through the support of a specialist librarian, learn computing skills, keep in touch with the outside world through the provision of free internet and Wi-Fi, or just sit and relax in a welcoming environment. We are ensuring that more and more resources are available online for people directly affected by disability and for the wider community. These include the ‘Back on Track’ handbook and CD-ROM (an introduction to spinal cord impairment for patients and their families) and Head Space: a handbook on brain injury and stroke. We are currently working on e-book versions of these resources which will be accessible via the NZST website.

**Volunteers**

The library is staffed by a 0.6 FTE library manager and a 0.5 FTE library assistant. Obviously 1.1 FTE staffing cannot provide the range of services described above. Integral to the user centred focus is the role of the library volunteers. Some assist in the library in a sole charge role.
role, enabling a weekend service to be offered, while others provide computer tuition for patients/clients attending courses at the ABC. This volunteer ‘resource’ where people help people provides opportunities for individuals to be of service to others.

The use of volunteers has been an innovation in the development of the ABC Library allowing the growth of volunteers as a ‘staff’ group without financial cost to the library. As a result of the success of the library volunteers, it was decided to establish a more formal training programme in ABC library duties and processes including a job description. This has proved highly successful.

**Collaboration**

Collaboration is an integral part of a holistic approach. The support from the various collaborating agencies such as the Christchurch City Libraries has been invaluable, in particular for people who had been discharged from the hospital it meant that they could access services from a branch nearest to their homes.

**Discussion & Conclusion**

In conclusion, the ABC model is a means to an end. It encourages the willingness to collaborate and co-operate by all the stakeholders, and by community resources including public libraries, and uses this willingness in a constructive way. As a result, much was achieved in the short term which has been sustained long-term. The ABC library has created interest from out patients and community groups, and further work is being planned to expand on this.

Information about the different projects and activities run by the New Zealand Spinal Trust currently: the ABC Library, Patient Education, Volunteers, Assistive Technology, Vocational Rehabilitation, Research can be found on the website at [www.nzspinaltrust.org.nz](http://www.nzspinaltrust.org.nz)

**References**


