An International Overview of Resource Centers on Disability

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Facilities variously known as independent living centers, disabled living centers, disability information centers, and resource centers now exist in many parts of the world. Although occupational therapists offer valuable perspectives on quality of life, knowledge of assistive technology, and a holistic view of clients' needs, occupational therapy is not always a part of these centers. Occupational therapists themselves may overlook these settings as venues for their services. This overview of 38 resource center organizations in 14 countries reports on their approaches to supporting persons with disabilities, professionals, and other members of the public and explores the presence of occupational therapy and other professions in these agencies.

Literature Review

The Cumulative Index to Nursing and Allied Health Literature (CINAHL) from 1983 through October 1992 lists 21 references to resource centers. Examples include a "self-care learning resource center" for cancer patients in Houston, Texas (Peterson, Michas, & Villajo, 1989); a continence center in Glasgow, Scotland (Dawes, Cherry, Ballentine, & Glen, 1991); and the Caregiver Resource Center for senior citizens in Cleveland, Ohio (Kerson, 1989). No CINAHL entries are indexed both for resource centers and for occupational therapy or occupational therapists.

Channels for contact between independent living centers and medical rehabilitation programs have been shown to benefit clients of both organizations (Fuhrer, Dossi, Gerken, Nosek, & Richards, 1990). Among the services offered by U.S. and Canadian independent living centers are information resources and access to assistive technology ("Independent Living," 1992; Mathews, 1990). Informed assistance by health professionals in selection of assistive technology, as well as adequate information and trial opportunities before selection or purchase of equipment, are noted to affect subsequent use of equipment and client satisfaction (Parette & Van Biervliet, 1991; Parker & Thorslund, 1991; Rogers & Holm, 1992).

Occupational therapists have much to offer to health promotion, both in community settings and through networking (Hurff, Lowe, Ho, & Hoffman, 1990; Madill, Townsend, & Schulz, 1989), yet in the United States only 46% of independent living centers use occupational therapy services (Bowen, 1992). Adults with cerebral palsy express the need for occupational therapy assistance from "independent living systems" as well as "medical rehabilitation systems" when asked to reflect on their experiences with both settings (Kibele, 1989). In a paper presented in 1970 at the 5th International Congress of the World Federation of Occupational Therapists, Barbara Stowe, then director of the Disabled Living Foundation in London, advocated the establishment of equipment and information centers in every country (Independent Living Centre of Western Australia, 1988). In Sweden, 157 out of the total 3,080 occupational therapists specialize as technical aids counselors working in technical aids centers (Parker & Thorslund, 1991). The American Occupational Therapy Association (AOTA) published position papers advocating for occupational therapy involvement in the independent living movement (AOTA, 1992), in assistive technology (AOTA, 1991), and in long-term care (Arn, 1992).

As one of nine occupational therapists employed by Rehabild, a resource center for persons with disabilities in Hong Kong, I wanted to know about similar resource organizations in other parts of the world, including their services, target groups, staffing, governing bodies, funding, philosophies, and links to other local, national, and international organizations. I was particularly interested
in learning about occupational therapy input in these centers.

Method

I compiled a list of agencies from individuals, from Rehabilitation mailing lists, and from publications such as DPI Independent Living Newsletter: Closing the Gap 92 Organizational Resources Directory, OT Week, AOTA's Independent Living Information Packet, and Independent Living, a publication of the Independent Living Centre in New South Wales, Australia. Organizations from 21 nations were included, but I limited the number from any one country to avoid a disproportionate weighting of results. A few agencies were selected over others in the same countries because I anticipated opportunities for firsthand contact during planned visits to these cities.

Information was initially collected by mail. A six-page questionnaire with an explanatory letter and information about Rehabilitation was sent to 81 resource centers or agencies. The questionnaire consisted of 10 questions with 60 subcategories. Multiple-choice lists were provided for each subcategory item so all positive responses could be indicated with a pen stroke. Spaces for comments were provided within each section. Respondents were asked to give a brief statement about the focus and philosophy of their organization. Before the first mailing, four practicing occupational therapists in Hong Kong gave feedback on the questionnaires and accompanying letters. Advice on how to document results was sought from a market research analyst.

Replies were received from 38 agencies, for a return rate of 47%. These 38 responding institutions, which are located in 14 countries, were then sent a two-page questionnaire that included additional questions, requests for clarifications of information from their previous reply, and a working definition of resource center for their comment. Twenty-four agencies replied a second time. Information from questionnaires was supplemented by six direct visits, by correspondence, and by publications of the responding agencies sent by respondents.

Working Definition of Resource Center

The term resource center was defined on the basis of replies to the first questionnaire. This definition includes the input of 15 of the surveyed agencies:

A resource center is a not-for-profit agency providing services and information or advice on aspects of living with effects of disability to people with disabilities, their families, and others interested in disability issues. Services are intended to be objective and impartial and are directly available although prospective clients may also be referred by individuals, rehabilitation professionals, or other organizations. Public education is a service component.

The best criteria for deciding which organizations were resource centers are whether they provide "response to telephone inquiries" and "public education" or "professional education." (One exception was included after correspondence with the respondent—a professional training center without direct consumer access that does not respond to telephone inquiries from the public.) Organizations that focus on specific disabling conditions were not included in the initial contact list and subsequently are not among those described in this paper.

Survey Results

The 38 organizations who replied to the first questionnaire are listed by country in Appendix A. Information about their services, groups served, staffing, governing bodies, funding, occupational therapy input, cooperation with other organizations, and philosophies are reported below.

Services

Some resource centers are highly specific—for instance, the Stockholm Cooperative for Independent Living is concerned primarily with provision and management of paid personal assistance, and the Great Lakes Technical Assistance Center provides information regarding the Americans with Disabilities Act of 1990. Other centers provide a wide range of services, including occupational therapy and problem solving, "financial belief" counseling, self-defense training, assistive technology, and training of therapists for rehabilitation of disabled children. Personal assistance (i.e., paid assistance with activities of daily living) is a service component for six agencies and the primary activity for one.

The largest subgroup, 22 of the 38 centers (58%), provides information on assistive technology, which includes equipment, aids and technology, and access to equipment for trial use. Twenty agencies (53%) offer equipment exhibitions full time or occasionally. One agency specializes in "advanced technology only," and two focus on computers and communications technology. Computer databases on equipment are part of the equipment—technology information in 14 agencies (37%).

Libraries were listed as a public resource in 27 agencies (71%). Books, audiovisual items, and journals were the most frequently mentioned resources, but other items available for library loan included monographs, computer software and hardware, toys, and assistive listening devices. Twenty agencies (53%) reported being involved in professional assessment, but only 7 described treatment as part of their activities.

Public education was a role of 28 centers (74%), and 22 (58%) reported that they were involved in professional education. Twenty-six agencies (68%) organized workshops and short-term training.
Target Groups

Thirty-five agencies (92%) directly serve people with disabilities. The remainder provide coordination or training for direct service providers. People with physical disabilities are a target group of all replying centers. Persons with sensory impairments (i.e., visual or hearing losses) are served by 31 agencies (82%), persons with multiple disabilities by 29 (76%), persons with intellectual or cognitive impairments by 24 (63%), and persons with psychiatric disorders by 21 (55%).

Thirty-one agencies (82%) serve health professionals, and 27 (71%) serve education professionals. Twenty-seven agencies serve students, with tertiary level students (that is, university, college, or technical school beyond high school) mentioned most frequently. Twenty-seven agencies are directly available to the general public. Other target groups mentioned included parents, manufacturers of equipment, employers, and social workers.

Staffing, Governing Bodies, and Funding

All but 1 agency reported having paid staff; 23 use volunteers. Twenty-eight different professions were represented on the agencies’ staffs, with occupational therapy appearing more than twice as often as the next most frequently listed professions, physical therapy and speech therapy (see Table 1).

Thirty-one agencies answered the question regarding the percentage of staff members who have disabilities. Totals range from 0% to 100%, with an average of 31%. Five agencies have no policy regarding hiring people with disabilities, while 25 reported giving preference to people with disabilities. One agency for children with disabilities gives hiring preference to parents of these children. An additional agency is in the process of developing an equal opportunity policy. Others noted that their hiring criteria are skills and, in one case, that every staff member must be ready to do every task, including lifting and transfer assistance.

Twenty-three agencies replied to questions regarding the percentage of members of the governing body who have disabilities. Figures range from 0% to 100%, with an average of 47%.

Centers usually receive funds from more than one source, including government (26 agencies), donations (24 agencies), and larger parent organizations (6 agencies), and by fees-for-services (18 agencies). Thirteen agencies indicated in the second questionnaire that they share their location and facilities with other organizations.

Occupational Therapy Input

Occupational therapists are staff members in 18 of the 38 centers described (47%), including 15 (68%) of the 22 aids-equipment-assistive technology centers, a treatment center, a consumer-controlled agency, and one unclassified center. All the state Independent Living Centres in Australia are staffed primarily by occupational therapists and exist “as a result of a single commitment by the occupational therapy profession” according to Louise van Willigen, Honourary Secretary of the Australian Committee for Independent Living Centres (personal communication, May 1992). In contrast, it was startling to learn that seven centers that emphasize assistive technology advice do not have occupational therapy input. These seven agencies are located in countries regarded as having well-developed occupational therapy services—Canada, Singapore, Taiwan, the United Kingdom, and the United States (3 agencies).

External Cooperation and Future Links Desired

Respondents reported numerous ways their centers cooperate with other agencies. For example, the eight Australian Independent Living Centres share a common logo, meet regularly, and are developing common computer systems. Respondents reported links with at least 11 international organizations outside their own countries (see Appendix B). Six centers did not indicate any

Table 1

<table>
<thead>
<tr>
<th>Profession</th>
<th>Number of Centers</th>
<th>Percentage of Centers Employing This Profession</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounting</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Administration (unspecified)</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Architecture</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Child care (unspecified)</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Computer applications technology</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Design and fabrication</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Education technology</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Engineering</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Fundraising, marketing</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Human services (unspecified)</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Independent living</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Industrial design</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Information science</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Legal</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Librarianship</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Medicine</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Nursing</td>
<td>4</td>
<td>11</td>
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<tr>
<td>Occupational therapy</td>
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<td>47</td>
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<td>18</td>
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<td>Policy</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Psychology</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Rehabilitation, health care</td>
<td>(unspecified)</td>
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</tr>
<tr>
<td>Social work</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Sociology</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Special education</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>8</td>
<td>21</td>
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<tr>
<td>Systems science</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Therapy (unspecified)</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
participation in national or international coordinating organizations.

Future links with other agencies were desired by 24 respondents who wanted exchanges of publications with similar organizations. Eighteen responded that they would like to receive "dedicated publications for resource centers" (one reported already receiving these). Twenty-four expressed interest in reciprocal visits among centers, but two had reservations regarding the costs of such visits. Additional comments toward future links included recommendations for international meetings and invitations for staff members of one center to visit another.

**Purposes and Philosophies**

The following contrasting statements illustrate the variety of focus and intent among this group of resource centers.

The Stockholm Cooperative for Independent Living (STIL, Stockholm, Sweden) is a user cooperative and a business which organizes private home helper services. STIL considers itself a civil rights organization of persons with disabilities.

At Progress Center for Independent Living (Oak Park, Ill.), we subscribe to the Independent Living philosophy, which moves individuals with disabilities out of a dependent and passive role, and into one of fulfilling their potential as productive, contributing members of society. We promote and encourage self-employment for individuals with disabilities in their efforts to live full lives within the community of their choice. Our Center is "consumer controlled," which means the majority of board and staff are individuals with disabilities, and that the Center's programs respond to this population's needs. We work to increase public awareness about disability issues and seek to improve conditions, accessibility, and policies in the community as a whole.

The Independent Living Centre (Victoria, Australia) aims to assist people with disabilities to enhance their independence and quality of life by providing advice and information on daily living aids and equipment.

**Study Limitations**

This survey was based on responses from an original sample of convenience. My limited expertise in forming the questionnaires should be taken into consideration in considering the results.

**Discussion**

This topic merits further research. The original mailing list was assembled before I knew of the international list of groups involved with the setting up or running of Disabled Living Centers or Information Centers produced by the Disabled Living Council in England. I also learned during the study from Robert Rosenfeld (personal communication, September 1992) of his list of "3,200 organizations working with people with disabilities in countries with less resources." (Rosenfeld is a collaborator on Project Projimo and the Hesperian Foundation, two community user-run rehabilitation groups.) The Disabled Living Council list did not include 8 of the 22 agencies dealing with equipment and assistive technology centers identified here and included only 2 of the other 19 agencies in this study. Obviously, few of the 3,200 organizations known to Rosenfeld are part of this study.

The language used to describe work and target groups varies from country to country and even from center to center and is an understandably sensitive issue. During one visit, I was emphatically told that assistive technology and technical assistance are completely separate. An Independent Living Center in the United States has much in common with the Handicaps Welfare Association in Singapore, whose motto is "Of the disabled, by the disabled and for the disabled," but is a completely different type of organization from an Independent Living Centre in Australia.

Although occupational therapists are not the only experts on disability, we are experts on aspects of living fully with disabilities. It would be a loss to persons with disabilities and to our profession for occupational therapists to abdicate this role to other professions or even to consumer groups of persons with disabilities. Resource centers that are directly available to users with disabilities are part of independent living systems (Kibele, 1989) rather than the traditional medical-rehabilitation systems where most occupational therapists work. Comments from some respondents to my draft definition suggested excluding "self-help groups," which I equate with "consumer controlled" centers. I think these distinctions are dangerous if they limit our thinking to traditional settings. The role of independent living centers in providing equipment advice was noted by Philip Draper of the Center for Independent Living in correspondence as well as in relevant publications ("Independent Living," 1992; Mathews, 1990), but occupational therapy is not a core service in the legislation that supports American independent living centers (Bowen, 1992).

**Recommendations**

This report examined a sample of convenience of 38 resource centers on disability in 14 countries. Services, target groups, staffing, governing bodies, funding, external cooperation, and philosophy statements were reported. Particular attention was given to learning about occupational therapy input reported in these centers.

Occupational therapists can offer resource centers insights and techniques for people living with disabilities. Any organizations that profess to provide expert information on activities of daily living and equipment selection and use should have occupational therapy input. As occupational therapy professionals, we need to show how our skills can enhance the services of community resource
centers. In turn, we can benefit from working outside medical model institutions in settings where persons with disabilities are leaders and advocates for others with disabilities.

Acknowledgments

I thank the Rehabaid staff and other colleagues in Hong Kong. I also thank the respondents, especially my hosts at the six organizations I visited: Geneva Cohen of the Disabled Living Foundation, John Chaplin of the Rehabilitation Resource Center, Kimberly Gerein of Progress Center for Independent Living, Margaret Lundquist of the Easter Seal Society, Glenn Hedman of the Assistive Technology Unit, and Cheryl Youngsworth of Great Lakes Disability & Business Technical Assistance.

An earlier version of this paper was presented at OT Into the Future: Hong Kong International Occupational Therapy Conference, September 12–16, 1992 (organized by the Department of Rehabilitation Sciences, Hong Kong Polytechnic, and the Hong Kong Association of Occupational Therapists).

Appendix A

Organizations Responding to the First Questionnaire

Australian Council for Rehabilitation of the Disabled (ACROD), ACT, Australia
Independent Living Centre, ACT, Australia
Independent Living Centre, Rede, New South Wales, Australia
Independent Living Centre of WA, Inc., Shenton Park, WA, Australia
Independent Living Centre, Brisbane, Queensland, Australia
Independent Living Centre, South Melbourne, Victoria, Australia
Microcomputer Application Centre, South Melbourne, Victoria, Australia
Kinsmen Rehabilitation Foundation of British Columbia, Vancouver, BC, Canada
Technical Resource Center, Calgary, Alberta, Canada
China Disabled Children Rehabilitation Training Centre, Beijing, China
Guangzhou Federation of Handicapped Youth, Guangzhou (Canton), China
Rehabaid, Kwunlon, Hong Kong
Rotary Rehabaid for Children, Hong Kong, Hong Kong
Independent Living Hungary, Budapest, Hungary
Indian Association of the Handicapped, Lucknow, India
M.I.L.B.A.T., The Israel Center for Technology & Accessibility, Tel Hashomer, Israel
New Zealand Disabilities Resource Centre, Palmerston North, New Zealand
Handicaps Welfare Association, Singapore, Singapore
Disabled People South Africa (DPSA), Capetown, South Africa
Stockholm Cooperative for Independent Living, Stockholm, Sweden
Operation De-Handicap, Taipei, Taiwan Republic of China
Aids Centre, Belfast, Northern Ireland, United Kingdom
Biv Yan Annahyono Independent Living, C м а r m а thе n, Wales, United Kingdom
CATCH UP (Cooperative Action to Change and Hurry Up Progress), Dyfed, South Wales, United Kingdom
Disabled Living Foundation, London, United Kingdom
National Demonstration Centre, Wakefield, Yorkshire, United Kingdom
Rehabilitation Resource Centre, City University, Londen, United Kingdom
Royal Association for Disability and Rehabilitation, London, United Kingdom
Assistive Technology Unit, University of Illinois at Chicago, Chicago, Illinois, U.S.A.
Center for Independent Living, Berkeley, California, U.S.A.
Computer Assistive Technology Service, Fort Worth, Texas, U.S.A.
Easter Seal Society of Metropolitan Chicago (Gilchrist-Marchman Center), Chicago, Illinois, U.S.A.
Great Lakes Disability & Business Technical Assistance Center, University of Illinois at Chicago, Chicago, Illinois, U.S.A.
National Rehabilitation Information Center (NARIC) and ABLEDATA program, Silver Spring, Maryland, U.S.A.
National Information Center for Children & Youth with Disabilities (NICHCY), Washington, DC, U.S.A.
Progress Center for Independent Living, Oak Park, Illinois, U.S.A.
Services for Independent Living, Inc., Euclid, Ohio, U.S.A.
Techspan Program, Resource Centre for Independent Living, Utica, New York, U.S.A.

Appendix B

International Organizations Linked to Respondents

AHRTAG, Appropriate Health Resources and Technologies Action Group
Alliance for Technology Access
CP-ISRA, Cerebral Palsy-International Sports and Recreation Association
DPI, Disabled Persons International
European Network for Independent Living
FESFIC, Far East South Pacific Games Federation
Fidonet
ICTA, International Commission on Technology and Accessibility (RI)
International Society for Prosthetics and Orthotics
ISAAC, International Society for Augmentative and Alternative Communication
RI, Rehabilitation International
UNICEF, United Nations Children's Fund

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