Community Based Rehabilitation (CBR)

and

Independent Living (IL)

This chapter is important for two reasons. First, many professionals in the disabilities field seem to equate the two programs. The second reason is that the few authors who do write on this subject only address it briefly.

Americans pride ourselves on our independence. We, as a nation, try to instill in our children, a sense of independence. It seems, however, that CBR has proliferated in countries where inter-dependence is the 'way of life'. As noted by Werner (1997), IL is built on the western value of living alone or independently. In societies with a strong sense of community, inter-dependence or living together is a more welcome goal.

Independent Living, as the name suggests, focuses on independence. In our society independence has many connotations. For various reasons though, people are not considered legally independent or considered to be capable of independence until the age of 18, or in some cases, 21. For example, in many states children must attend school through grade 12, which for most people means age 18. Only after that are they considered independent to choose whether or not to go to school, and in the case of post-secondary education, which school. Perhaps because that is the earliest age a person can enter into a lease or home purchase agreement, it seems that is the earliest acceptable age that a person can be considered independent.

IL services are focused on helping people with disabilities live independently. That usually means making choices such as where to live, who to hire as an attendant, and entering into contractual obligations such as apartment leases or purchasing assistive services or technologies. Having worked at two IL Centers and having attended many IL conferences, I can say without hesitation the vast majority of services were provided to people age 18 and older. Although services were occasionally provided to those under age

18 or to family members of a child under age 18, the vast majority of services were provided to people age 18 and older. CBR services, on the other hand, are geared toward all ages, especially children and even prenatal as with disability prevention.

CBR has a program for children - specifically early intervention and treatment. See the Chapter on Portage. Although the Portage model is not universally used in all CBR programs, services for children is a common theme in CBR programs. IL programs are rarely involved with such services; when service does take place it is usually in the form of Information and Referral, not direct service as in CBR.

The issue of control seems to differentiate CBR from IL. According to Lysack & Kaufert, (1994) "The CBR model is one of conjoint development or partnership; IL ideology places control squarely with disabled consumers." They go on to point out, (p239) pragmatics of real-life often overcome ideologies and we must question to what extent is the average person with disability involved with decision-making in the field? The issue of consumer control may be more of an illusion than reality in both schemes. Lysack & Kaufert, (1994) asserts that in the IL movement, decision-making power to affect these changes rests with 1-2% of elite disabled-consumer leaders.

According to Werner (1997), the IL's strength is social action for equal opportunities, led by disabled activists. Its biggest weakness is that it is largely a middleclass movement and has left out the poor or their needs are misinterpreted to fit priorities of Western disability activists. Werner (1997) also notes CBRs' biggest strength is that it tries to reach all people with disabilities, especially those in greatest need. He also said though that disabled people are seen as objects to be worked on, not leaders, organizers and decision-makers.

Table 3 CBR and IL Comparison

Issue	Program	
	Community Based Rehabilitation	Independent Living
Builds on	Inter-dependence	Independence
Services for children	Yes	Very little
Primary ages served	All ages	Mostly over 18
Consumer controlled	Not necessarily	Yes
Strength	Reaches those in greatest need	Disabled define needs, demand rights
Weakness	Organized for, not by disabled	Middleclass oriented, poor are left out
Primary Intervention*	Yes	No
Secondary Intervention	Yes	No
Tertiary Intervention	Yes	Yes

^{*}see the chapter on prevention for clarification

Given a choice, to Lysack & Kaufert, (1994) say the majority of people with disabilities in developing countries, particularly where people are unlikely to receive any rehabilitation in their lifetime, would choose CBR over IL. IL may be perceived to be of lower priority to consumers and communities who have yet to receive primary care services. They are more likely to adopt an approach that such as CBR that:

- 1. detects, diagnoses and explains their problem,
- 2. makes recommendations for primary treatment and referral, and
- 3. provides some aids and adaptations. (Lysack & Kaufert, 1994)

I believe the same can be said for those living in poor, rural areas of the U.S.

There are areas on the U.S, - Mexican border that may be considered 'third world'. In

Texas for example, there is an area on the border called the Colonias. It has no running

water or electricity let alone a city hall at which one could petition the need for accessible parking places. At this point in their development, CBR would be a higher priority.

In the future, Werner (1997) says one of the biggest challenges is to link the empowering self-determination of the IL movement with the broad outreach to the poor as characterized by CBR. I believe this is part methodological and part cultural. If CBR can be incorporated into communities, I believe there will be no need for ILs. Ideally, integration of people with disabilities should be so entrenched in the fabric of our society that there is no need for specialized services such as IL. If the tenets of CBR are observed, every medical, social, vocational and educational program will fully incorporate people with disabilities. As written by Davies (1997,p3) "The integration of people with disabilities into society has priority of creation of special environments and specialized services for them". We will know we are fully integrated when one's disability is noticed, but is not a barrier to participation.

Reference:

Davies, Michael (1997, June) Community-Based Rehabilitation Work – Christoffel Blinden Mission (CBM).pg 2, Unpublished paper, 16 pages, Manila, Pilippines

Lysack, Catherine; Kaufert, Joseph (1994, September) Comparing the Origins and Ideologies of the Independent Living Movement and Community Based Rehabilitation. International Journal of Rehabilitation Research; v17 n3 p231-40

Werner, David (1997) <u>Nothing About Us Without Us: Developing Innovative Technologies For, By and With People with Disabilities</u>. HealthWrights, Palo Alto, California.