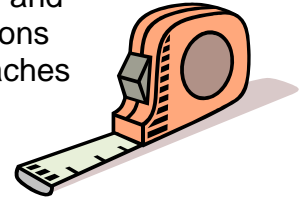


Emerging Disability Groups into the Independent Living Paradigm

Background: Under the new disability paradigm, social, behavioral, and environmental factors play a far greater role in helping to define persons with disabilities than in the past. From existing measurement approaches that define impairments at the organ level or document functional limitations in daily living, efforts to define the disabled population should now include linkages with social determinants of health and environmental components. One implication of this new approach to looking at disability is that previous numerical estimates persons with disabilities may be inaccurate using existing data sources. In addition, strategies to optimize efforts at successful independent living may currently not place appropriate emphasis on environmental management, and place too great an emphasis on personal care or medical management, to the possible detriment of the overall health status of many segments of this newly-defined population.



Research questions:

1. How do centers for independent living provide services to people with emerging disabilities?
2. What more can centers for independent living do for people with emerging disabilities?

Purpose and anticipated benefits: Guiding this research were the goal of developing an understanding of characteristics that distinguish emerging from existing disability populations and also the goal of identifying data sources that allow accurate measurement of these groups. This information can be used to identify the service needs of emerging disability groups and to compare these needs to more traditionally-defined people with disabilities.



Who: Project Director Michael Fox, Sc.D., (as viewed in photograph to the left) with KyungMee Kim, Ph.D., and Robert Meade, J.D., interviewed 102 people with disabilities recruited by centers for independent living in Kansas by phone surveys and focus groups.

When: 2002

Method: Data from consumer interviews, focus groups, and follow-up surveys were analyzed by using constant comparative analysis. Population based health data using the 1999 Medical Expenditure Panel Survey (MEPS) (N=4,170 persons with any disabilities) to try to distinguish differences between emerging and traditional disability

populations incorporated both qualitative and descriptive techniques. Extensive feedback from persons with disabilities at our national advisory meetings guided finding interpretation as did input from the full staff of Independence Inc., a center for independent living in Lawrence, Kansas.

Results: From focus groups and consumer interviews, we noted the themes of difficulty in accurately diagnosing; implications with respect to employment, social services, and interpersonal relations; fear of unproductive lives; and the physical, emotional, and mental aspects of emerging disabilities. Four broad themes emerged from the consumer interviews as characteristics of emerging disabilities with measurement implications: medical acceptance, invisibility to society, pain as underlying many emerging disabilities, and self recognition leading to broader understanding. After discussions with opinion leaders, the following also emerged:

- There appears to be a connection between the need to identify emerging disabilities and the strength of their constituent interest groups.
- Perception among groups representing emerging disabilities was that their condition is short-term. Also noted were the transition between individuals' search for a "cure" and the need to promote independent living.
- Bridges are needed between the medical community and the independent living movement; the medical community could serve as extensions of independent living philosophy under the right conditions.

Table 2. Differences between emerging and non-emerging disability populations identified using the Medical Expenditure Panel Survey (n = 4160; AHRQ, 1999)

Factor	Variable	Category	Disability status		P value
			Emerging disabilities (n = 97)	Non-emerging disabilities (n = 4063)	
Demographic	Age (Mean)		53	54	
	Marital status (%)	Married	47	51	
		Others	53	49	
	Race (%)	White	79	83	
		Non-white	21	17	
Gender (%)	Male	50	45		
	Female	51	55		
Function	Education year (mean)		10.3	11.4	< 0.01
	# of ADL(Mean)		6.9	5.5	< 0.01
	Lifting (%)	No difficulty	15	36	< 0.01
		Difficulty	85	64	
	Walk 10 steps (%)	No difficulty	12	32	< 0.01
		Difficulty	88	68	
	Walk 3 blocks (%)	No difficulty	5	18	< 0.01
		Difficulty	95	82	
	Walk 1 mile (%)	No difficulty	4	12	< 0.05
		Difficulty	96	88	
	Standing (%)	No difficulty	11	27	< 0.01
		Difficulty	89	73	
	Bending (%)	No difficulty	3	24	< 0.01
		Difficulty	97	76	
	Reaching (%)	No difficulty	16	45	< 0.01
		Difficulty	84	55	
	Grasp (%)	No difficulty	43	63	< 0.01
Difficulty		57	37		
Insurance	Type of insurance	Medicare	34	43	
		Medicaid	45	21	< 0.01
		Private insurance	36	56	< 0.01
Health Care Use	Office-based provider visit (mean)		14.4	10.2	< 0.01
	Outpatient dept. provider visit (mean)		6.8	4.1	
	Emergency room visit (mean)		1.6	1.5	
	Hospital discharge (mean)		1.4	1.6	
Employment	Employment status (%)	Employed	17	41	< 0.01
		Unemployed	83	59	
	Hourly wage (mean)		10.00	12.71	

All mean comparisons were analysed using Student's *t*-test; differences in percentages were analysed using Chi-squared test.
 Screening for persons with disabilities in the MEPS was done using following criteria: all persons with disabilities criteria—any limitations such as ADLs, IADLs, activity, functional or sensory limitations; emerging disabilities criteria—fair or poor perceived health status, fair or poor perceived mental health status, do not use assistive devices, have some social limitations, have some work limitations. Criteria taken from focus group experience.
 Non-emerging = all persons with disabilities – persons with emerging disabilities.

After analyzing demographics between persons we coded as having a disability and those whose disability was consistent with characteristics our focus groups identified as "emerging," the following results were found: Persons with emerging disabilities tended to have less education, have greater difficulties with activities of

daily living, be insured more frequently with Medicaid (indicating lower income), have less private insurance, see doctors for medical care more frequently, and are much less likely to be working.

Conclusion: Emerging disabilities cannot accurately be defined: they are impossible to accurately measure at the present time. Also, service providers, both medical and social, appear reluctant to extend services to persons with disabilities they have difficulty categorizing; societal understanding of poorly-defined disabilities appears dependent upon expanded peer support, social action, clinical acceptance, and legal protection. As for centers for independent living, they can expand their role into one that recognizes, accepts and supports emerging disability groups. And, according to study results, they could focus on outreach, disability awareness, health referral, employment assistance, and improved home help.

Quotation: “Findings from our research reinforce the need to rethink how disability is typically viewed in society. Emerging disabilities are in some ways artifacts of political intent, both in their formation and subsequent recognition by broader segments of people both in and out of the disability community. While many interest groups of persons with disabilities are highly vocal in their desire to disconnect their disability from medical diagnosis and treatment, groups of persons with disabilities perceived as emerging stage their early battles for this very turf, hoping that medical acceptance will lead to greater societal acceptance. As a portal for larger recognition, it appears that all disabilities must pass through some level of medical understanding before being more widely understood in the working world, in communities, or even by persons having these sometimes poorly defined conditions themselves.”

Project output:

- Fox, M.H., & Kim, K.M. (2004, June). Understanding emerging disabilities. *Disability and Society* 19(4), 323-337.
- Kim, K.M., & Fox, M.H. (2004, March). Knocking on the door: The integration of emerging disability groups into independent living. *Journal of Vocational Rehabilitation* 20(2).
- Fox, M.H., & Mead, R. (2004, Fall). The relationship of disability to employment protection under Title 1 of the ADA in the United States Circuit Courts of Appeal. *The Kansas Journal of Law and Public Policy* 13(485).
- Kim, K.M., & Fox, M.H. Moving to a holistic model of health among persons with mobility disabilities. *Qualitative Social Work: Research and Practice*. Accepted for publication November/2005.

- Presentations: “Identifying Persons with Disabilities under the New Paradigm.” Department of Health Policy & Management Seminar, January 11, 2002; “Medicare and Medicaid: Implications for Stroke Survivors,” 11th Annual Stroke Survivor Conference, Kansas City, Mo., May 4, 2002; “Medicare and Medicaid: Implications for Persons with Parkinson’s Disease”; Kansas City, Kansas Parkinson’s Support Group, June 10, 2002; RTC/FPIL National Advisory Group, Kansas City, Mo., October 24, 2002; Working Conference on Independent Living, Kansas City, Mo., October 26, 2002; Disability Forum, American Public Health Association, Philadelphia, Pa., November 11, 2002; national partners meeting held in Kansas City, Mo., October 30, 2003.