

Social services utilization by adults with intellectual disabilities and their families[☆]

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Abstract

In this study, we used Andersen's Behavioral Model with the family as a unit of analysis to examine the patterns of awareness and utilization of social services by families with at least one adult with intellectual disabilities. Face-to-face interview questionnaires were conducted with primary family caregivers in Hsinchu City, Taiwan in 2004. Data were collected on adults' and caregivers' predisposing, enabling, and need variables as well as awareness and utilization of formal social services. A total of 792 interviews were completed, making a response rate of 94.2%. Multivariate logistic regression analysis was used to identify potential predictors of social service awareness and utilization. We found awareness and utilization to be mostly associated with predisposing and enabling variables including caregiver's socioeconomic status, family connection with social networks, and family participation in related groups or associations. Younger caregivers were more likely to access formal assistance, while adults whose families were more connected into social networks were more likely to be aware of in-kind and voucher services, e.g., in-home services including respite and home care, and vocational services such as sheltered workshops, and bus voucher services.

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Introduction

About 80,000 of Taiwan's population of 23 million (3.4 per thousand) has been diagnosed with intellectual disabilities (Department of Social Affairs, Ministry of Interior, ROC, 2005). Taiwan's amended Disability Act of 1997 is one of its most important pieces of disability welfare legislation and it outlines social policies and services for adults with intellectual disabilities. Since its enactment, local authorities have provided

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formal social services for people with disabilities, though the availability of such services in some non-metropolitan areas is often limited. And in these areas, as well as metropolitan areas, formal social services for households with members who have intellectual disabilities are underutilized.

Recent studies on adult populations with intellectual disabilities have articulated their health care needs and utilization of services that meet those needs (Hayden, Kim, & DePaepe, 2005; Janicki et al., 2002; Lin, Wu, & Lee, 2003; Majnemer, Shevell, Rosenbaum, & Abrahamowicz, 2002; Reichard, Sacco, & Turnbull, 2004; Yu, Huang, & Singh, 2004). However, there is a relative lack of studies that focus on social service utilization by these people, especially by those adults who live with their families.

In Taiwan, most people with intellectual disabilities (93%) live with their families (Department of Statistics, Ministry of Interior, ROC, 2003). Social services are often not utilized because people are unaware of them (Fu, Chou, Hong, & Cheng, 2000; Lin, Leu, Chou, & Tsao, 1995). If the parents of a person with intellectual disabilities have a higher educational level and belong to related voluntary associations, they might apt to better use social services, a finding by Chou and Tzou (2004) studying users of respite care. These studies are limited, however, in that they either target people with various disabilities (not just adults with intellectual disabilities) or they focus on utilization of specific types of social service (e.g., respite care) rather than on the entire range of social services, which may be equally important because some recipients of social services are family members, not just the adults with disabilities.

The original Behavioral Model, developed to understand families' use of health services, posits that utilization can be explained by predisposing, enabling and need components of the family (Andersen, 1968). In that study, Andersen (1968) considered the family an appropriate unit of study because it is the primary earning, spending and consuming unit in our society and it is often the unit that makes care seeking decisions. Besides, the need for medical care often changes through the family life cycle (Andersen, 1968). For the same reasons, this model can be applied to investigating family use of social services. In addition, for persons with intellectual disabilities, it is often the family members rather than the persons with intellectual disabilities who are making the actual care decisions.

Previous studies have found that utilization of social services depends not only on the impairment of the

care recipients but is also influenced by the characteristics of the caregiver in the family, the characteristics of the family (e.g., socioeconomic factors) and the resources available in the community (e.g., access issues) (McCarthy, Ewashko, & Mackenzie, 1998; Osberg, DiScala, & Gans, 1990). This is particularly true for recipients of care living with their families. Studies have also found that the needs of the caregiver are significant determinants of whether or not services are used, while family enabling factors are the most important predictors of the amount of services used (Bass & Noelker, 1987).

The Behavioral Model has been used by several Western studies on the utilization of formal social or health services by the elderly (Bass, Looman, & Ehrlich, 1992; Chapleski, 1989; Krout, 1984; McAuley & Arling, 1984; Miller & McFall, 1991; Ozawa & Tseng, 1999; Spence & Atherton, 1991). These studies have found the determinants of service utilization to be (1) predisposing variables such as user's age, education level, sex, race, marital status and living arrangements; (2) enabling variables such as user's family income, contact with other community agencies and availability of transportation, kinship networks, awareness of services, geographic location, and social support networks; and (3) need variables such as users' level of cognitive impairment, activities of daily life (ADL) and burden on the primary caregiver.

Because it was not until recently that most local authorities in Taiwan, including Hsinchu City Government, started to provide in-home and vocational social services, this study aims to investigate the possible determinants of awareness and utilization of social services by adults with intellectual disabilities and their families living in Hsinchu City. We used the original Behavioral Model as a reference to structure our research and to examine the applicability of this model in the social services area. Because a family must be aware of the availability of social services in order to use them, we included awareness as an enabling factor in the Behavioral model. In addition, since awareness should not be taken for granted, we also included possible determinants of family awareness of available social services.

Several points regarding social services provided by Hsinchu City Government for people with disabilities are important when designing this study (see Appendix 1). First, family subsidies for family with members with disabilities at home are only available for low income families, defined by government means-test as either "poor" or "near poor." This

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