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AUTHOR	Strobino, Jane
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ABSTRACT

The study examined family support services currently utilized by families of individuals with developmental disabilities, and family support services seen as important by respondent families in the state of Hawaii. A total of 625 questionnaires were distributed via 24 agencies; 234 useable surveys were returned for a 39% response rate. The survey instrument contained items related to demographic characteristics of respondents, demographic characteristics of the developmentally disabled individuals, utilization of family support services, and identification of important family support services. Findings indicated that most of the developmentally disabled in the sample were between school age and young adulthood and enrolled in a day training or activity program. Major diagnoses included multiple handicaps, mental retardation, and learning disabilities. Most respondents were mothers between the ages of 31 and 61. The most used services were financial and medical assistance, adult day program, and transportation. Family support services not used but wanted included information and referral, advocacy, parent support groups, and counseling. Identified as most important services by respondents were respite, day program, leisure/recreation programs, and information/referral. (DB)

Family Support Services in Hawaii:
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Jane Strobino, D.S.W.
Assistant Professor
Marywood College
School of Social Work
Scranton, Pennsylvania 18509

Introduction

The recognition of the role that families play in the habilitation of individuals with developmental disabilities has led to the development of family support services (Castellani, Downey, Tausig, & Bird, 1986; Perlman, 1983). Family support services include those services other than those basic residential/vocational/habilitative services that people with developmental disabilities require for normal community living (Castellani et al., 1986). The intent of family support services is twofold: to enhance the ability of the family to provide care; and to enrich the quality of care received by the individuals with developmental disabilities.

The literature related to family support services has addressed a variety of issues including: types of services; utilization of services; availability of services; and accessibility of family support services (Castellani et al., 1986: Gelman, 1974; NYSCQCMD, 1985; Salisbury & Intagliata, 1986).

Types of family support services involve both tangible (such as day programs, respite, and financial assistance) and non-tangible (counseling, support groups, and information and referral) which may be provided directly to the individual with developmental disabilities or to family members.

The extent to which families have used family support services, particularly respite, may not be as extensive as service providers have expected, and certainly the use of some family support varies with the age of the individual with developmental disabilities.

Although a range of family support services may appear to be available, accessibility to these services sometimes creates additional burdens for families. These burdens or barriers include costs of services, scheduling of services, actually getting to the location where the service is provided, and the awareness by the parent that the service exists or the manner in which to obtain services.

Services that have been identified consistently by families as helpful include: respite care, parent support groups, and information and referral services.

Family support services are in place in Hawaii. However, currently there is no empirical information about parents' views about family support services. Thus, the purpose of this study was to document the parents' perspective about their use of family support service and their identification as to important family support services. Such information is important in order to develop a service delivery system that is truely responsive to the needs of the consumers.

The Study

This was a one group exploratory study of families with individuals with developmental disabilities who were enrolled in some type of habilitation program. The major factors examined were: characteristics of the individuals with developmental disabilities; characteristics of the respondents; current family support service utilization pattern; and parent perspective as to important family support services.

The main questions that this study attempted to answer were: (1) what family support services are currently being utilized ?; and (2) what family support services are seen as important by these respondents?

The population pool for this study included all individuals with developmental disabilities who were affiliated with one of twenty-four survey agencies. Due to a number of constraints including budget and time, a non-random sampling plan was employed. Surveys were distributed to twenty-four agencies throughout the State of Hawaii and the agency directors were asked to distribute the surveys to the parents. A total of six hundred and twenty-five (625) questionnaires were distributed, and two hundred and thirty-four (234) usable surveys were returned for a 39% response rate. Data collection occurred between January and March, 1987.

The survey instrument contained items related to demographic characteristics of the respondents, demographic characteristics of the individuals with developmental disabilities, utilization of family support services, and identification of important family support services. This instrument was reviewed by a parent and a member of the DD Council and was found to be readable and unobtrusive.

There are a number of methodological factors that pose limitations to the study. These include: the non-random sampling plan which can impact on the representativeness of the sample and thus the ability to generalize the findings; the exploratory nature of the research design and thus the inability to test out relationships; and the data collection methodology which resulted in a low response rate and the incompleteness of the surveys which raises questions as to the respondents' ability to understand and accurately complete the items.

Despite these limitations, this study does provide valuable information about parental use of and perspective of the important family support services.

Findings

Table 1 displays a summary of the frequency distributions of the characteristics of the individuals with developmental disabilities. Overall, this sample included individuals who were mostly between school age and young adulthood and who were enrolled in some type of day training or activity program. The major diagnoses for this group included multiple handicaps, mental retardation, and specific learning disabilities.

Table 2 depicts a summary of the frequency distributions of the characteristics of the respondents or primary caregivers. Generally, the respondents were married mothers between the ages of thirty one and sixty one. Income was fairly evenly distributed among all income categories with approximately half of the respondents earning less than $21,000 per year. More than half of the respondents reported two or more wage earners and more than half of the respondents lived on the island of Oahu. The major ethnic groups represented in this sample included Caucasians, Japanese, and Filipinos. Nearly all of the respondents had some affilitation with a religious group and nearly two thirds of the respondents indicated that someone was home during the day to care for or supervise the individual with developmental disabilities.

Tables 3-A, B, and C show the utilization patterns of a variety of family support services as indicated by the respondents. The family support services being used most are tangible services such as financial and medical assistance, Adult day program, and transportation.

Family support services not being used but wanting to be accessed by the respondents included information and referral, advocacy, parent support groups, and counseling.

Table 4 identifies those family support services considered to be important by the respondents. Overall, both tangible and non-tangible services were identified as important to this group of respondents. Tangible services were respite, day program, and leisure/recreation programs whereas non-tangible service was information and referral.

Comments by respondents to an open ended question about what specific services would be helpful were: an information booklet that is current and gives specific information about eligibility criteria, fees, etc.; twenty-four hour hotline regarding emergency and regular services; network current services among agencies so that a continuum of services over the life cycle exists; train service providers about other services so that information and referral can be timely and appropriate; and educate the public about developmental disabilities so that community integration can be facilitated.

Discussion

Because the majority of this sample of individuals with developmental disabilities was between the ages of four and thirty four, we may not be getting a very clear indication of service needs for the very young and recently diagnosed, or the middle age and elderly populations of individuals with developmental disabilities. The service needs of these age groups may be quite different from those groups surveyed. Therefore it would be important to document the service needs of these age groups for comparison and planning purposes.

The fact that for most of the sample diagnoses included mental retardation and multiple diagnoses suggests a group of individuals who will probably require some type of regular and ongoing care or supervision. Consequently, since parents are identified as primarily responsible for assuring that care and supervision, the continued presence, assessment, and development of family support services is critical.

Although the majority of the respondents were parents and primarily mothers, there were a fair number of respondents who were care home operators. It should be recognized that whoever is the primary caregiver for individuals with developmental disabilities, they should be sustained in that caregiving role by the availability of support services. Therefore, in light of the development of community living options, it would be important to assess not only the service needs of this group of caregivers, but also service utilization and service accessibility. Such information is vital since there is some evidence that individuals with developmental disabilities will receive more services if placed out of the home than if kept at home (NYSCQCMD, 1985). If this is the case, then the service system may inadvertently discourage families from continuing on as primary caregiver.

Given that most of the respondents were of or approaching middle age, and that aging may have an impact on the ability to provide care, it seems particularly important to assure that support services be readily available to those parents so as to sustain them in the caregiving role for as long as possible. Furthermore, a service such as "lifetime planning" for the individual with developmental disabilities may be especially appropos.

The finding on education suggests that families have a variety of ways of understanding the diagnoses and service system. One way involves reading materials. In view of this fact and the fact that respondents wanted more information, coupled with the concept that parents strive to be independent and competent in problem solving (Slater & Wikler, 1986; Strobino, 1987), the availability of written materials about the range of suppport services should be facilitated.

The high percentage of intact marriages among this sample may mean that the respondents have a built in support system for both the physical caregiving and the social-psychological adaptation to the role of primary caregiver. Supporting this idea the fact that the majority of the respondents indicated that someone was home during the day. Additionally, the ethnic composition of this sample and the life style within this State may involve living arrangement such that extended family members living within or close to the family home. Such a situation may impact on both the perceived and real need for particular support services, specifically respite.

The income distribution was relatively even across all income categories although a small percentage was identified as being either very poor or wealthy. These two income groups often have the best access to support services---the poor through federal/state eligibility subsidy, and the wealthy through purchase of service or insurance programs. Thus, this sample includes a fairly large group that might be deemed the "gap" group that may not be able to afford to purchase services and who are ineligible for "free" services.

The majority of the respondents were from the island of Oahu, and the reality is that most of the services are located on this island. Services, agencies and programs are limited on the outer islands and thus families have to "make do" with what is available. Planning for services would need to take on a creative approach so that a range of support services could be make available and accessible to all island residents in a cost effective manner.

The fact that nearly all of the respondents were affiliated with some religious group suggests that the religious organization may be a viable structure within which to support families. The religious organization can be seen as a resource for addressing both the physical and psychological demands of caregiving as well as a resource in educating the community to take responsibility for supporting the care of individuals with developmental disabilities. Additionally, the religious organization may be helpful in outreach especially to immigrant families who may not know of the service system, or in identifying to service providers, families who may benefit from outreach services.

The current pattern of service utilization indicates that families are using tangible services such as adult day program, transportation, financial assistance, and medical assistance. Interesting is the fact that these "support" services are targeted directly to the individuals with developmental disabilities and not the parents. Yet, the parents are indirectly supported through the utilization of these services. This finding supports previous literature that suggests that parents strive to be independent in caregiving, want to be viewed as competent in their caregiving, and therefore may actually perceive "support" when it is their children who in fact are the direct recipients of the services.

This speculation about parental need to feel competent is further supported by the finding that parents wanted to use non-tangible services, especially information and referral. This type of service targets the parents directly and reinforces the perception that parents can very adeptly carry out the primary caregiver role.

The tangible services that parents wanted to use, in-home respite and leisure/recreation programs do address the physical demands of caregiving that parents experience, and are consistent with the findings of previous research on family needs regarding support services (Salisbury & Intagliata, 1986; Upshur, 1982). Certainly there are models of in-home respite care that can be adapted for implementation in Hawaii.

Families prioritized respite services, information and referral (including parent support groups), and day program as the three most important family support services. These prioritized services are consistent with the services identified by respondents as those that they wanted to use.

Summary

This was an exploratory study that attempted to document parental utilization and perception of important family support services in the State of Hawaii. Despite methodological limitations, the results of this study provide a beginning understanding of how parents use and view family support services. Recognizing and utilizing the consumer perspective in the ongoing planning and development of family support services should result in an efficacious service delivery system.

Certainly further empirical documentation about the major issues relevant to family support services is essential for planning purposes. Additionally, implementation of specific recommendations made by parents that would improve services is important if parents are to be encouraged to engage in the service evaluation and planning process.

Finally, the cooperative efforts of parents, professionals, agency personnel and representatives of the larger service delivery system that made this study a reality suggests a potential for ongoing collaboration to implement a rational planning strategy in supporting parents of individuals with developmental disabilities.

Table 1

Summary of Frequency Distributions of Characteristics of the Individuals with Developmental Disabilities

Age	Range Less than a year old to 61 years
	Mean 19 years
Gender	53% Males
	46% Females
Diagnosis	35% Multiply Handicapped
	34% Mental Retardation
	10% Specific Learning Disability
Daytime Program	45% Adult Day Program
	28% Department of Education Program
	20% Infant Stimulation Program
	7% Not Enrolled in any Program

Table 2

Summary of Frequency Distributions of Characteristics of Respondents

Respondents	66% Mothers 20% Fathers 14% Other (mostly Care Home Operators)
Age	Range 20 years to 77 years Mean 46 years
Marital Status	73% Married 26% Not Married
Education	Range 2 Grades to Graduate School Mean High School Education
Income	49% Less than $21,001 51% Greater than $21,001
Number of Persons Contributing to Income	38% One 47% Two
Ethnicity	30% Caucasian 25% Japanese 14% Filipino 11% Hawaiian/Part Hawaiian
Religion	38% Catholic 26% Protestant 15% Other (Christian) 13% Buddhist
Someone at Home During the Day	62% Yes 37% No
Residence	51% Oahu 21% Kauai 16% Hawaii 10% Maui

Table 3-A

Summary of Frequency Distribution of Current Service Utilization

Service	No Need	Need	Currently Using
In-Home Respite	160	50	5
Out-of-Home Respite	135	39	42
Babysitting	136	44	32
Personal Care Services	192	16	8
Chore Services	189	20	7
Residential Services	167	25	15

Table 3-B

Summary of Frequency Distribution of Current Service Utilization

Service	No Need	Need	Currently Using
Adult Day Program	118	14	81
Leisure-Recreation Program	91	56	71
Transportation	105	25	94
Equipment	154	18	28
Financial Assistance	85	39	94
Medical Assistance	70	31	120

Table 3-C

Summary of Frequency Distribution
Current Service Utilization

Service	No Need	Need	Currently Using
Advocacy	92	58	55
Parent Training	106	37	63
Counseling	115	48	50
Genetic Counseling	152	22	25
Information & Referral	75	60	73
Parent Support Groups	88	57	64
Crisis Stabilization	146	47	16

Table 4

Summary of Frequency Distribution
Service Priorities

Service	Number
Respite, Babysitting, or Personal Care Services	N = 95
Information & Referral	N = 92
Day Program	N = 79
Leisure Activity - Recreation Programs	N = 60
Transportation and/or Equipment	N = 52
Specialized Therapy	N = 48
Financial Assistance/Medical Insurance	N = 38
Residential Care Services	N = 23
Community Education/Resource Development	N = 9

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