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A decorative graphic consisting of two overlapping, semi-transparent geometric shapes: a light green trapezoid on the left and a light blue trapezoid on the right, both pointing towards the right.

Independent Life for People with
Disabilities Residing in the Community:
The Role of the Family

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February 2007

Abstract

This paper examines the main issues encountered by family members living with and alongside people with severe physical disabilities who reside independently in the community. The discussion is based on a review of the professional literature, as well as on a process of mapping needs of families of severely disabled adults (aged 21 to 64 years). Interviews were conducted with people who have various disabilities and with members of their families, as well as with academic professionals and practitioners in the field. The interviews reveal a clear need to develop services and promote solutions for those families.

There is both a lack of ancillary services and resources for people with severe disabilities to help them live independently in the community. This shortcoming derives primarily from social barriers related to attitudes and accessibility, as well as the absence of appropriate social arrangements that would facilitate independent living. The gap is filled through informal support from family members, who are the natural source of support for people with severe disabilities. This can be a positive situation because family members have intimate knowledge of the disabled person and can help the individual cope with the challenges of living with his or her disability. However, family members do not receive social recognition, or appropriate support for their efforts. Regardless of whether they provide support willingly or out of necessity, family members lack sufficient tools to concurrently maintain their own quality of life. As partners, they are also affected by the tremendous difficulty of the disabled family member's living an independent life in the community. They share the burden and themselves need solutions for dealing with the disabilities.

By nature, people who live with and alongside family members with disability are faced with a heavy burden. Their own emotional agenda is largely related to the demands that arise from this life situation. The main factors that shape this agenda are the extent of the family member's functional disability and functional independence; health disorders that are specific to and derive from the chronic disability (dependent upon the disability type, nature, and course of events); perceptions of disability as a challenge or as a stressor; the quality of interpersonal relations and support; social barriers that affect attitudes and accessibility (in the context of work, financial arrangements, leisure activities, enrichment, etc.); the existence and accessibility of personal and community resources; the ability to develop coping skills and handle situations within and outside of the family. Another related issue is the gap between the disabled person's desires and the more limited lifestyle and opportunities actually available to him or her (e.g., entering the labor force, being part of society, or taking advantage of opportunities in life) as compared to those of members of the same cohort who do not have disabilities.

The repercussions of inadequately acknowledging the needs of family members of people with disability are manifested at the level of policy, social norms, and relations within the family. Within the family issues that arise include role overload, (e.g., filling the dual role of family member and primary caregiver), marital relationship and parenthood, and differences in beliefs about independence, partnership, involvement and intervention, giving and receiving help, decision-making, etc. These issues must be dealt with in addition to the tremendous investment that family members make in the attempt to facilitate the burden of disability in a mutual way.

There are many facets of family empowerment, including empowering the person with disability to function as a family member (e.g., as a parent or spouse); the family to attain a balance in assisting the disabled member; and the person with disability to regard him or herself as an equal partner in a network of mutual support that is concerned with the well-being of all family members.

The recommendations presented in this paper focus on promoting processes and providing adequate tools to enable people with disabilities to live independently. There is a need to empower these families by developing policies, establishing an organized, practical, and accessible body of knowledge on the topic, promoting issues of family relationships, and training professionals to intervene for families.

With regard to *developing organized policies*, there is a clear need to make policy makers more aware of the shared needs of people with severe physical disabilities and their families. Such policy should define the family as the natural provider of ancillary services to disabled persons, and entitle the family, as such, to these services. These policies can strengthen families, enhance their functioning, and even give them the tools to strengthen themselves. This approach would reduce the burden and stress on families and facilitate their social participation (e.g., in terms of employment, social and leisure activities, and parenting). The process of developing policies involves identifying the sources of power and stakeholders who can promote the issue; examining the gaps between existing legal policy provisions and their implementation; facilitating dialogue between policymakers and representatives of families; allocating budgets for establishing a body of knowledge to focus and define the needs of the families; and developing the required ancillary services as a result of the above process.

To *establish an organized and practical body of knowledge* requires defining the status and needs of the family in the context of theoretical developments which consider the disabled person's abilities, right to exercise those abilities, and entitlement to engage in a range of social roles and maximize social participation in every respect. This body of knowledge can include examination of the relationships between the disabled people and their families as a mutual system that reinforces and strengthens itself, as opposed to viewing the family as a unidirectional resource for

enabling independent living. Allocation of resources for research would help broaden existing strategies and develop efficient methods for coping with long-term processes of chronic disability, in order to generate models for interdisciplinary evaluation. Such evaluation could consider possibilities for expanding the disabled person's functioning and strengthening the parties involved in assisting with functioning at home and in the community.

In the first stage, experimental groups of families would receive a basket of ancillary services. Their needs would be evaluated, and the impact of the ancillary services on their well-being assessed. An adequate body of knowledge would facilitate the training of professionals in the field and ensure therapeutic continuity in the transition from hospitalization to residence within the community.

Another recommendation for empowering families is to **provide and ensure accessibility to information** about life situations, entitlements, and services. This would provide knowledge about, control over, and awareness of every aspect related to independent life in the community. That goal requires establishing an information site on the Internet, publishing books and articles that describe real life experiences, and producing guidebooks to help families deal with their life situations. To promote knowledge and accessibility of information it would be worthwhile to establish discussion groups to identify and address family needs and organize study days and workshops on specific topics.

We emphasize the need to *strengthen family relationships* through methods such as therapeutic services; counseling, guidance, and dissemination of information on issues that affect family members; a self-help system among families; and a process of interdisciplinary evaluation throughout the life cycle to better integrate community services. Family relationships would also benefit from the development of methods to define interpersonal experiences generated by these life conditions and skills for work in a team where everyone is given equal space. Attitudinal changes would result from portraying experiences of those with disabilities as natural and universal. To further these processes, it is necessary to *train professionals* in a family-oriented and system-based approach through basic training programs, continuing education, and training in small work teams. In addition, there is a need to formulate definitions that emphasize the unique activities of professionals who work with and deal with disabled people and their families.

The full report in Hebrew and the abstract in English can be downloaded from:
www.jdc.org.il