

**THE DOLLARS AND SENSE OF
PROMOTING THE SELF-SUFFICIENCY
OF PERSONS WITH DISABILITIES
THROUGH PROGRAMS OF INDEPENDENT LIVING,
IN-HOME AND FAMILY SUPPORTS
EXECUTIVE SUMMARY**

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Introduction

In June of 1990, the Pennsylvania Coalition of Citizens with Disabilities completed a two year planning process resulting in a plan entitled "A Plan for Comprehensive Services for People with Physical Disabilities." This plan is intended to provide and ensure access to services that will enable people with physical disabilities to lead more independent, productive lives in socially integrated communities; in short, to enjoy full citizenship. The plan was formulated in large part by persons with disabilities. The cornerstones of the plan are two:

- The creation of state level agencies, one within state government and one without, to coordinate independent living, in-home and family support services for people with disabilities and to advance their interests, and
- The adoption of protocols for the control of services by the persons with disabilities for whom the services are intended.

All of the programs targeted for state coordination in the plan, the Community Services for People with Physical Disabilities (CSPPPD) Program, the Independent Living Program, the Attendant Care Program and the community living support program (proposed) are generally termed "in-home and family support services." These programs, designed to allow individuals with disabilities to live, work and contribute as full citizens in their home communities, stand in sharp contrast to the more traditional congregate care arrangements. Historically, individuals in need of public services have had to move out of their home towns and into group living and work places populated solely by other persons with disabilities. As this brief shows, not only are such approaches unfitting a just society, they are inconsistent with current economic imperatives and are decidedly uneconomic when compared to programs of in-home and family support.

This brief presents strong evidence that providing integrated in-home and family support services for people with disabilities is cost effective.

- First, given labor shortages in the human services field in Pennsylvania and nationwide, present and future, in-home and family supports which require fewer paid professionals than traditional congregate care arrangements (e.g., nursing homes, group homes...) are a must, an economic imperative.
- Second, in-home and family support services generally cost less to provide than do congregate care arrangements.
- Third, in-home and family support services have been shown to allow individuals with disabilities to obtain gainful employment and thus contribute to their care and to the public tax base.

- Fourth, in-home and family support services reduce the costs associated with lost career opportunities for family members and with the stress that comes with trying to meet the needs of family members with disabilities unaided.

The Economic Imperatives of In-home and Family Supports

In-home and family support services require fewer paid professionals than do traditional congregate care arrangements and they mine what manpower is required from existing labor pools far more efficiently than do congregate care arrangements. Given the already limited and still shrinking labor pool from which care providers can draw in Pennsylvania, these features are critical.

One compelling reason to promote in-home supports is the widely forecast labor shortage of the 1990s — a labor shortage that looms large in the human service industry (Task Force on Human Resources Development, 1989).

With the possible exception of those requiring 24-hour care, in-home and family support services are less staff intensive than congregate care arrangements for several reasons. They don't have to employ groundskeepers, housekeepers and other ancillary personnel to maintain a facility. They can arrange for paid assistance only when that assistance is needed. Particularly important, in-home and family support services demand that the individuals themselves, with the help of family members and friends, be as self sufficient as possible. What supports are provided are intended to complement and supplement, not to supplant personal efforts.

In-home and family support arrangements also have a recruiting advantage. Part-time workers, (e.g., roommates, companions, care attendants) can be recruited in many neighborhoods far more easily than can full-time workers.

In-home and Family Support Services are More Cost Effective Than Congregate Care Services

The cost of providing in-home and family support services to people with disabilities is generally less than the cost of serving these individuals in nursing homes, group homes and other traditional congregate care facilities; at the same time users of in-home and family support services become more self sufficient than do residents in congregate care arrangements.

This is evident in:

- comparative analyses of the costs of congregate care and family care arrangements for adults and children with disabilities (Ashbaugh & Nerney, 1990);
- comparative analyses of the costs of hospital care and in-home care for medically involved children (McGauley, 1989; Knoll & Bersani, 1990);
- comparative analyses of the costs of congregate care and supported living programs in selected states throughout the country (Pennsylvania Economy League, Inc, 1988; Taylor, 1987; Smith, 1990; and Racino, 1989);
- a review of Home and Community Based Waiver programs (e.g, Illinois, Wisconsin, California, and Texas), and
- comparative analyses of the costs of care for individuals with disabilities prior to and following their moves from congregate care to independent living arrangements as described by the Centers for Independent Living in Pennsylvania and in other states.

In-home and Family Support Services Lead to Employment and Attendant Economic Benefits

Independent living, In-home and Family Supports allow individuals with disabilities to obtain gainful employment, and to become more productive members of their home communities. The rise in the availability of supported work programs should allow even more individuals with disabilities to enter the workplace, so long as their living situations permit.

Studies show that when persons with physical disabilities receiving in-home supports they are more likely to seek and obtain paid employment (Conservation Company, undated; United Cerebral Palsy of Pennsylvania, 1989; and Kimmich, forthcoming). Further studies show that when persons with disabilities obtain or are helped to obtain paid employment public benefits are realized in the form of increased tax payments, and in the form of reductions in public outlays for human service programs, health insurance and income subsidies (Conley and Noble, 1990; Vogelsburg, Guthier, Berry and Ross, 1990; Thornton and Decker, 1990).

Family Supports Can Reduce Public and Social Costs Related to Family Stress and Dysfunction

Family support services can provide the relief needed for family caregivers not to have to forego valued career (economic) opportunities, and the support needed to keep family members and the family unit from reaching the breaking point (e.g., nervous breakdowns, divorce) with the attendant public and social costs.

Raising a child or caring for an adult with disabilities can take a toll on family resources both financially and socially. The financial disadvantage is in part explained by the loss of income earning opportunities that families experience in the course of caring for a family member with disabilities (Agosta, 1990; Agosta, forthcoming). These losses are not the families' alone; they mean less tax revenue and more demands for indigent supports. Aside from the direct effects on family income there are social costs of caring for a persons with a disability that can lead to higher public costs (e.g., mental health care and substance abuse treatment) (Mace, 1986; Litvak, Zukas and Heumann, 1987).

However, the provision of family supports and subsidies can noticeably alter this picture. Studies show that family support services allow family members to maintain or regain employment, save marriages, reduce family stress, and reduce the number of families seeking out-of-home placement for their dependents with disabilities (Conservation Company, Undated; Allard, Spence and Bradley, 1986; United Cerebral Palsy of Pennsylvania, 1989).

Conclusion

The economic arguments in favor of in-home and family support services are many. In-home and family support services are less costly to provide than are congregate care services, they better position individuals to take advantage of education and employment opportunities with rewards both to the individuals themselves and to the taxpayer, and they allow family caregivers to manage the care of family members with disabilities without the needless sacrifice of their own careers, undue stress and dysfunction. Even more, far more sparing in their use of paid professionals than congregate care arrangements, in-home and family support services make sense in the face of the shrinking pool of available labor widely forecast for the nineties.

This brief makes a convincing case for providing in-home supports and subsidies to individuals with disabilities and to caregivers of individuals with disabilities. This approach to configuring services for persons with disabilities is not only dignifying and empowering but is rational and cost effective.