

“Money can’t do everything – but it can do a lot. My son’s needs are intense and overwhelming at times. The program is a godsend.”

“Through the HBSSP, we have been able to make some much needed adaptations to our home that have increased safety and mobility.”

“Our daughter needs 24 hour care. As much as we love her, she drains our energy since we are now seniors. We are able to keep her home and she now enjoys new faces and different experiences.”

## Evaluation of a Model Consumer-Directed Program: Illinois

Over 75% of individuals with developmental disabilities live at home. One third of the family caregivers are over the age of 60 years. Yet, funding for family support accounts for less than 4% of funding nationally within the developmental disabilities service system. Over the last decade states have made committed efforts to support individuals living at home with families. One example of such an effort is the Illinois Home Based Support Services Program (HBSSP) which is a model consumer-directed program for adults with developmental disabilities and their families. The program is considered “consumer-directed” because it provides families with an individualized budget of approximately \$1,500 per month to design and direct supports. There are currently 19 similar consumer-directed programs within the United States. However, unlike Illinois, many of these programs focus only on children.

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities has conducted research on the Illinois HBSSP since it was developed in 1990. The research sought to answer three questions: 1) What services are families using? 2) What benefits do the families receive? and, 3) What is the impact on out-of-home placements?

### Most Used Services

The most frequently purchased services include:

|                     |                         |
|---------------------|-------------------------|
| Respite             | Recreational activities |
| Transportation      | Therapies               |
| Vocational training | Home modifications      |

### Benefits to Participants

Families participating in the program found the following benefits:

- Fewer unmet service needs
- More satisfaction with services
- Increased confidence in their ability to provide care
- Increased employment of mothers
- Greater community involvement for persons with DD
- Increased employment and higher wages for persons with DD
- Decreased family desire for out-of-home placement

“The program improves my daughter’s quality of life. The program has increased her independence, providing things we couldn’t afford. It has enhanced her social life and given her opportunities to make choices and be in control of her life.”

“The HBSSP is a life-saver. I was able to go out for the first time, anywhere, without my son, and he will be 49 this year.”

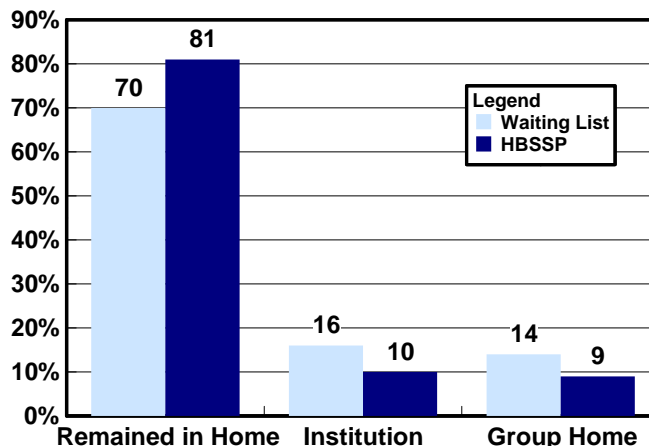
“The HBSSP has made it possible for my son to remain at home rather than in a state facility.”

## Impact on Out-of-Home Placement

The study compared the placements of 301 individuals in the HBSSP with 835 individuals on the waiting list between 1995 and 2003. The program resulted in *a significant reduction in out-of-home placement for HBSSP participants.*

- In 1995 all individuals with developmental disabilities were living at home.
- In 2003 only 70% of the individuals on the waiting list were still living at home versus 81% of the individuals in the HBSSP.
- Enrollment in the HBSSP resulted in a significant reduction in institutional and nursing facility placements. Sixteen percent of the individuals on the waiting list were placed into institutions versus 10% of the individuals in the HBSSP.

**Out-of-Home Placement of Individuals on Waiting List versus Individuals in HBSSP**



For more information:

- Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 47(4/5), 352-366.
- Heller, T., Miller, A.B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Family Relations*, 48, 405-410.

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