Involvement of Adult Siblings of People with Developmental Disabilities in Future Planning

Planning for the future is a central task for aging adult siblings of people with developmental disabilities and their families. Adult siblings of people with developmental disabilities are the most likely people to be involved in the future as parents age and can no longer provide care. Yet many parents are reluctant to involve their children with or without disabilities in future planning (Heller & Caldwell, 2006).

This study asks: 1) To what extent are siblings involved in future planning? 2) What factors contribute to sibling involvement in future planning? 3) What factors contribute to sibling expectations of being a primary caregiver? 4) What are the concerns of siblings for the future? and 5) What supports do siblings need? We surveyed siblings through an online sibling support group and sibling conference. The 139 siblings who responded were predominately sisters (93%) who were highly educated (76%) with most (70%) living within an hour of their brother or sister with a disability. The variables addressed were respondents’ demographics (age, gender, ethnicity, educational level, and Activities of Daily Living and gender of the person with a disability); childhood emotional reactions; distance between siblings; involvement in disability activities; reciprocal support; sibling relationship involvement; and caregiving burden and satisfaction.

Sibling Involvement in Future Planning

Few families in this study made residential (32%), guardianship (39%), or financial plans (44%) or created a letter of intent, a non-legally binding planning document (44%). Only 32% of families had identified a future caregiver. Siblings who were most involved in future planning were those who were older and were already involved in disability related activities.

Whether or not families had completed plans, siblings were most likely to be involved in identifying future caregivers and in making residential plans. Siblings were less likely to be involved in formal tasks (i.e., establishing a special needs trust, creating a letter of intent, and establishing powers of attorney for their siblings with disabilities).
Sibling Expectations of Being Future Primary Caregivers

About 36% of the sibling respondents expected that they would eventually become the primary caregivers of their sibling with a disability. The non-disabled siblings were more likely to expect this role if their sibling with a disability lived closer to them and was a female. The non-disabled siblings were also more likely to expect this role if they were more involved in disability activities, had more contact with their sibling, and felt greater satisfaction in providing care for their sibling with a disability.

Concerns of Siblings for the Future

Siblings reported the following areas of concern for the future of their brother or sister with a disability:

- Personal costs: financial, time, relations with spouse/partner
- Dividing responsibility among family
- Death of parents: Worry about future responsibilities
- Their own death
- Availability of services (housing, benefits, recreation, respite, transportation)
- Sibling health, safety, and happiness
- Making sure sibling voices are heard
- Helping from a distance

Implications for Policy and Practice

With the aging of parent caregivers, professionals will be increasingly working with siblings, a constituency that to date has received fewer supports. Our study revealed that many siblings yearn for greater involvement in the lives of their siblings with disabilities, but need more information, networking opportunities, and supports.

For more information on future planning for individuals with developmental disabilities visit the Rehabilitation Research and Training Center on Aging with Developmental Disabilities http://www.rrtcadd.org
Visit http://groups.yahoo.com/group/sibnet for an online discussion group for adult siblings of people with developmental disabilities